

## What Motivates to Medicate?

A qualitative study exploring the factors that influence a parent's decision to select psycho-stimulants as first-line treatment for their ADHD child.

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Submitted in partial fulfilment of the requirements for the degree of Psychology Masters of  
(Counselling Psychology) in the School of Applied Human Sciences - Psychology

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## CONTENTS

Declaration	5
Acknowledgements	6
Abstract	7
<b>CHAPTER ONE:</b>	
<b>INTRODUCTION AND OUTLINE OF THIS STUDY</b>	<b>9</b>
1.1 Background and rationale for this study	9
1.2 Aims and objectives	10
1.3 Theoretical approach of this research	10
<b>CHAPTER TWO:</b>	
<b>LITERATURE REVIEW AND THEORETICAL FRAMEWORK</b>	<b>12</b>
2.1 Attention Deficit/ Hyperactivity Disorder: An overview	12
2.1.1 Diagnosis	13
2.1.2 Prevalence	16
2.1.3 Etiology	17
2.2 Assessing approaches to treatment	18
2.2.1 Psycho-stimulant use	21
2.3 Within a South African context	25
2.4 Treatment decision making	29
2.4.1 Decision making theory	33
2.4.2 Normative / prescriptive approaches	34
2.4.3 Descriptive approaches	35
2.4.4 Shared decision making	35
2.4.5 The Health Belief Model	37
2.4.6 The Theory of Reasoned Action and Planned Behaviour	40
2.5 In summary	42

## **CHAPTER THREE:**

### **METHODOLOGY 43**

3.1 Theoretical framework	43
3.2 Research design	45
3.2.1 Research participants and sampling	46
3.2.2 Data collection methods and instruments	47
3.2.3 Composing the interview guide	48
3.2.4 Data analysis methods	48
3.3 Ethical considerations	50
3.4 Validity and reliability	52
3.5 Limitations of the methodology	54

## **CHAPTER FOUR:**

### **DISCUSSION OF RESULTS 55**

4.1 Tabulated overview of the sample	56
4.2 The respondents	57
4.3 Factors that influence the decision making process	60
4.3.1 Knowledge of the disorder	60
4.3.2 Information sources	63
4.3.3 The role of the teacher	64
4.3.4 Acceptance / unacceptance of diagnosis	66
4.3.5 Parental beliefs, attitudes and perceptions	67
4.4 Motivators to medicate	70
4.4.1 Alternatives to stimulants	70
4.4.2 Confidence in an expert opinion	72
4.4.3 Pressure to medicate	73
4.4.4 A defining moment	76
4.5 Reflections as a co-creator	77

<b>CHAPTER FIVE:</b>	
<b>ANALYSIS AND INTEGRATION OF FINDINGS</b>	<b>79</b>
5.1 The decision making process	79
5.2 Application of the Health Belief Model	80
5.3 Application of the Theory of Planned Behaviour	87
5.4 Concluding comments	88
<b>CHAPTER SIX:</b>	
<b>CONCLUSIONS AND SUMMARY</b>	<b>89</b>
6.1 Summary of research findings	89
6.2 Conclusions	90
6.3 Contributions made by this research	91
6.4 Limitations of this research	91
6.5 Recommendations for future research	92
<b>REFERENCES</b>	<b>93</b>
<b>APPENDIX</b>	<b>102</b>
1 Ethical Approval	103
2 Letter of Introduction	104
3 Consent Form	105
4 Interview Guide	106
5 Individual Interviews	108

## DECLARATION

This dissertation is submitted in partial fulfillment of the requirements of the degree of Masters of Social Science (Counselling Psychology), in the Graduate Program in the School of Psychology, University of KwaZulu-Natal, Durban, South Africa.

I declare that this dissertation is my own work. All citations, references and borrowed texts have been duly acknowledged. This work has not been submitted before for any other degree or examination at any other university.

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## **ACKNOWLEDGEMENTS**

A very sincere thank you to Sachet Valjee, my research supervisor, for the invaluable guidance, encouragement, patience and hours of supervision that you have provided throughout this undertaking. Without you this project never would have happened. Despite the many demands on you, you always made time for me. I truly appreciate your insightful input and feedback and I look forward to working with you again.

A heartfelt thank you to my wonderful husband for all the support, patience and encouragement you have provided me with throughout my academic career but thank you most especially for giving me the time and space I needed in the final weeks before submission of this work.

Thank you to my fellow M1 students Shelley Rogers and Candice Leith for being part of this journey. The consistent support and motivation to keep going is sincerely appreciated.

Thank you to the staff at the University of KwaZulu-Natal's Department of Applied Psychology. The experience of working through your Masters program has been a privilege.

Lastly, and of course most importantly, I would like to thank the research participants as without you this dissertation would never have taken place.

## **ABSTRACT**

This research seeks to explore and identify the factors that influence a parent's decision to initiate psycho-stimulant treatment for their ADHD child. It is the intention of this research to gain insight into how parents make decisions about treatment for their child with ADHD and specifically, what motivates a parent to medicate. A qualitative methodological approach was employed. This research is informed by a critical, interpretive approach.

An extended personal interview was conducted, using a semi-structured interview guide, with ten parents of ADHD diagnosed children. Children with comorbid conditions (both psychological and medical) were excluded from the sample to control for drug interaction mediating treatment choice. Sample selection included a combination of purposive, quota and snowball sampling techniques.

The Health Belief Model and the Theory of Planned Action provide a useful theoretical framework guiding the analysis of data. Findings show that factors influencing the decision making process include: The information parents have and where that information comes from; the role of the teacher in the identification of issues; ADHD being the observer's interpretation of the child's behaviour and the beliefs, attitudes and perceptions parents hold regarding all aspects of ADHD.

Factors that motivate a parent to choose medication in treating their child diagnosed with ADHD include: The failure of alternatives including their inconsistent treatment effects; having faith in the expert opinion of the prescribing doctor; being encouraged to 'just try it'; a specific defining moment triggering a cue to action and pressure from a variety of sources.

Conclusions of this research confirm there are many diverse factors that influence both the decision making process of parents as well as a definitive decision to choose psycho-stimulants as treatment and that there is no single factor that can be identified as a motivator to medicate.

Other conclusions made include: Parents make ADHD treatment decisions based on misinformation from unqualified sources; diagnosis of ADHD remains contentious; the beliefs, attitudes and perceptions parents hold of ADHD and its treatment options play a role in their decision making process but these beliefs, attitudes and perceptions may be related to the misinformation parents have regarding aspects of ADHD and the decision to initiate stimulant treatment is both complicated and intricately related to the individual experiences.

Identifying and understanding the factors that motivate treatment decisions can assist physicians and other healthcare professionals in addressing the concerns parents have in managing ADHD. In addition to this, an awareness of the factors influencing parental decisions regarding medication magnifies the important role healthcare professionals have in providing accurate and current information to parents and families when they are faced with making decisions about treatment for their child with ADHD.

*Keywords:* Attention-Deficit/Hyperactivity Disorder, Psycho-stimulants, stimulants, methylphenidate.

[Please note, the terms psycho-stimulants and stimulants are used interchangeably]



## **CHAPTER ONE:**

### **INTRODUCTION AND OUTLINE OF THIS STUDY**

This is a qualitative study exploring the factors that influence a parent's decision to select psycho-stimulants as first-line treatment for their ADHD child.

#### **1.1 BACKGROUND AND RATIONALE FOR THIS STUDY**

Attention-deficit/hyperactivity disorder (ADHD) 'is one of the most common childhood psychiatric conditions' (Van der Westhuizen, 2010, p. 10). Its core symptoms of hyperactivity, impulsivity and/or inattention, which first present in childhood and may continue through adolescence into adulthood, can lead to numerous problems in academic achievement, vocational success, behaviour, personal relationships with family members and peers and low self-esteem. In addition to this, ADHD often presents as co-morbid with a variety of other disorders including oppositional defiant disorder, conduct disorder, anxiety, depression, tics and Tourette's syndrome, and epilepsy (Van der Westhuizen, 2010).

Left undiagnosed and untreated, ADHD negatively impacts on an individual's 'learning capacity, [their] family life, education, social interaction' and may lead to depression and / or anxiety (Danciu 2011, p.2968).

Danciu (2011, p.2968) writes: 'In addition to its central traits, [ADD/ADHD] can lead to a series of associated, secondary traits, such as: disorganization; poor social relations with [siblings] and children of the same age; aggressive behaviour; low self esteem and deficient self-knowledge; self-stimulation behaviour; daydreaming and absentmindedness; coordination deficits; memory problems [and] persistent obsessive thoughts'.

Stimulants are first-line in the pharmacological treatment of ADHD. Methylphenidate is the most common drug prescribed for this condition (Reiff, 2011).

Despite there being overall progress in terms of the assessment, diagnosis and treatment of ADHD, much controversy around the disorder still exists. The existence of ADHD, whether it can be reliably diagnosed and how it should be treated are topics of much debate. One of the major controversies surrounding ADHD relates to its treatment.

Psycho-stimulants in particular are now readily available and are being prescribed with increasing frequency. Diverse and conflicting opinions about the treatment of this disorder leave parents with difficult decisions to make in terms of how to best treat their ADHD child.

In reviewing available literature on ADHD, there is little research exploring the decision making process of parents when faced with having to treat their child diagnosed with this disorder. In addition to this, a significant gap exists in attempting to identify factors that motivate a parent to initiate psycho-stimulant treatment. It is within this area that this study seeks to contribute.

For the purposes of this study, diagnosis of ADHD will include Attention-Deficit/Hyperactivity Disorder, Combined Type; Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive Type and Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive-Impulsive Type. The same treatment approach options are indicated for all three named subtypes.

## **1.2 AIMS AND OBJECTIVES**

The proposed study seeks to achieve two objectives:

1. To understand the factors influencing a parents' decision making process when considering various treatment options for their child diagnosed with ADHD.
2. To explore the specific factors that motivate a parents' decision to select psycho-stimulants as the primary method of treatment for their child with ADHD.

## **1.3 THEORETICAL APPROACH OF THE RESEARCH**

For the purposes of this study, the *Health Belief Model (HBM)* and the *Theory of Planned Behaviour (TPB)* will inform a theoretical understanding of the factors mediating the decision making process in selecting psycho-stimulants as the preferred treatment approach. Together, these theoretical models will be used to guide the proposed study. In addition to this, the essence of this research is exploration and insight from the perspectives of the people involved. Concern is with the lived experiences of these people in context. Guided by the theoretical input, an interpretive framework will be applied.

Within the interpretive tradition, the focus is on the subjective understandings and experiences of individuals, committing to an examination of perspectives, uncovering meaning and sharing understanding (Terre Blanche, Durrheim and Painter, 2006). As this is the central achievement of qualitative research, an interpretive paradigm is well suited to this study.

## **CHAPTER TWO:**

### **LITERATURE REVIEW AND THEORETICAL FRAMEWORK**

This chapter reviews the literature deemed to be relevant to this study. The review of literature has been organised in terms of dominant themes appearing within various literary sources related to this study. As it is pertinent to this research, the theory of decision making has also been incorporated and discussed.

#### **2.1 ATTENTION-DEFICIT/HYPERACTIVITY DISORDER: AN OVERVIEW**

‘ADHD is the most researched of all childhood behavioural disorders with more than 1,000 scientific articles published yearly’ (Reiff, 2011). Snyman and Truter (2010, p.161) define Attention-Deficit/Hyperactivity Disorder (ADHD) as a syndrome of ‘developmentally inappropriate and socially disruptive behaviour, beginning in childhood and [being] characterised by varying degrees of hyperactivity, inattention and impulsiveness’.

Brinkman, Sherman, Zmitrovich, Visscher, Crosby, Phelan and Donovan (2009, p.581) describe ADHD as a common ‘neurobehavioural disorder’ affecting both children and adolescents, resulting in the impairment of academic, social, interpersonal and family functioning.

Antshel, Hargrave, Simonescu, Kaul, Hendricks and Faraone (2011, p.72) refer to ADHD as ‘the most commonly diagnosed behavioural disorder of childhood’, viewing it as a ‘neurocognitive behavioural developmental disorder most commonly seen in childhood and adolescence [and often extending] to the adult years’.

Given the agreed functional impairments, the effects of ADHD are pervasive across a variety of settings including scholastic performance, academic achievement, vocational success, family relationships and social-emotional development (Doggett, 2004). When studied across time, children diagnosed with ADHD are at higher risk for learning, behavioural, and emotional problems throughout childhood and adolescence (Doggett, 2004). In addition to this, ADHD is also associated with several comorbid conditions and disorders such as mood disorders, disruptive behaviour disorders and learning disabilities (Antshel et al, 2011).

### **2.1.1 DIAGNOSIS**

As a multidimensional disorder, ADHD is defined by persistent and maladaptive symptoms of hyperactivity/impulsivity and inattention (please refer to Table 1 for its full diagnostic criteria).

Diagnosis for this disorder is made using the criteria specified in the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, Text Revised (DSM-IV-TR). As a disorder, ADHD can present as the following subtypes:

- 1) ‘Attention-Deficit/Hyperactivity Disorder, Predominantly Inattentive Type. Symptoms indicating this type include: A failure to pay close attention to details or to make careless mistakes with schoolwork, work or other activities; difficulty sustaining attention; appearing not to listen when spoken to directly; not following through on instructions; failing to finish tasks, chores or duties; difficulty organizing tasks and activities; avoiding tasks requiring mental effort; being easily distracted, forgetful in daily activities and / or often losing / misplacing things.
- 2) Attention-Deficit/Hyperactivity Disorder, Predominantly Hyperactive-Impulsive Type. Symptoms indicating this type include: Hyperactivity – evident as: often fidgeting with hands and feet; unable to sit still; running and / or climbing excessively when inappropriate; restlessness; being constantly ‘on the go’; talking excessively; having difficulty engaging in quiet leisure activities. Impulsivity – evident as: interrupting or intruding on others; difficulty waiting turn and blurting out answers before questions have been completed.
- 3) Attention-Deficit/Hyperactivity Disorder, Combined Type. This type is indicated as including at least six symptoms of inattention and six symptoms of hyperactivity-impulsivity’.

(DSM IV-TR, 2000, pp.85-87)

As outlined in DSM-IV-TR (2000, p.85), the essential feature of ADHD is ‘a persistent pattern of inattention and/or hyperactivity / impulsivity that is more frequent and severe than is typically observed in individuals at a comparable level of development’. It is stipulated that to receive the diagnosis, the individual concerned must exhibit at least 6 core symptoms, before age 7, and these symptoms must cause some impairment in functioning in at least 2 settings, school and home for example, (severe impairment in one setting is also sufficient).

**Table 1: DSM-IV-TR criteria for ADHD**

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**A. Either 1 or 2**

*1. Six (or more) of the following symptoms of inattention have persisted for at least 6 months, to a degree that is maladaptive and inconsistent with developmental level:*

- a. Often fails to give close attention to details, or makes careless mistakes in schoolwork, work or other activities
- b. Often has difficulty sustaining attention in tasks or play activities
- c. Often does not seem to listen when spoken to directly
- d. Often does not follow through on instructions, and fails to finish schoolwork, chores or workplace duties (not due to oppositional behaviour or failure to understand instructions)
- e. Often has difficulty organizing tasks and activities
- f. Often avoids, dislikes or is reluctant to engage in tasks that require sustained mental effort (such as schoolwork or homework)
- g. Often loses things necessary for tasks or activities (for example, toys, school assignments, pencils, books or tools)
- h. Is often easily distracted by extraneous stimuli
- i. Is often forgetful in daily activities

*2. Six (or more) of the following symptoms of hyperactivity/impulsivity have persisted for at least 6 months, to a degree that is maladaptive and inconsistent with developmental level:*

- a. Often fidgets with hands or feet or squirms in seat
- b. Often leaves seat in classroom or in other situations in which remaining seated is expected
- c. Often runs about or climbs excessively in situations in which it is inappropriate (in adolescents or adults, may be limited to subjective feelings of restlessness)
- d. Often has difficulty playing or engaging in leisure activities quietly
- e. Is often 'on the go' or often acts as if 'driven by a motor'
- f. Often talks excessively
- g. Often blurts out answers before questions have been completed
- h. Often has difficulty awaiting turn
- i. Often interrupts or intrudes on others (for example, butts into conversations or games)

**B.** Some hyperactive-impulsive or inattentive symptoms that caused impairment were present before 7 years of age

**C.** Some impairment from the symptoms is present in two or more settings (for example, at school/work or at home)

**D.** There must be clear evidence of clinically significant impairment in social, academic or occupational functioning

**E.** The symptoms do not occur exclusively during the course of a pervasive developmental disorder, schizophrenia or other psychotic disorder, and are not better accounted for by another mental disorder (or example: mood disorder, anxiety disorder, dissociative disorder or personality disorder)

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*Diagnostic and Statistical Manual of Mental Disorders, Fourth edition (2000, p.92)*

Eighteen core symptoms of ADHD are listed in DSM-IV-TR. These are divided into the 2 major behavioural domains of inattention and hyperactivity / impulsivity and can be further described according to the subtypes detailed above (Predominantly Inattentive Type, Predominantly Hyperactive-Impulsive Type, and Combined Type). An additional category, ADHD Not Otherwise Specified (ADHD NOS) considers individuals who display fewer symptoms of inattention or hyperactivity / impulsivity than those who meet the full criteria for one of the other 3 subtypes, but who are nevertheless significantly impaired as a result of the symptoms displayed (Parens and Johnston, 2009; DSM IV-TR, 2000).

Danciu (2011, p.2968) refers to ADHD as a complex disorder that affects concentration, organization, motivation and emotional modulation, 'as well as one's memory and other functions related to the management of the brain's activities' where chronic symptoms may result in 'serious and long-lasting problems' relating to learning processes and relationships with others. As a diagnostic label, ADHD is a term used to name individuals who have 'different collections and levels of symptoms and who suffer different levels of overall impairment' (Parens and Johnston, 2009, p.3).

According to Parens and Johnston (2009, p.3), 'ADHD does not have a single, simply identifiable form, [it] is expressed differently in different children and it differs in severity from mild, to moderate, to severe'. Diagnosis of ADHD is therefore an observer's interpretation. Parens and Johnston (2009, p.3) explain: Many children assessed for ADHD occupy what can be referred to as a 'zone of ambiguity' where physicians, teachers, and parents may disagree as to the display of symptoms, the degree to which functional impairment is experienced and whether or not a diagnosis of ADHD is warranted.

According to Parens and Johnston (2009, p.3), increasing rates of ADHD diagnoses (and the resultant increased use of stimulant treatment) have contributed to increasing concerns that many children found in the zone of ambiguity are diagnosed as having ADHD rather than being referred to as 'simply different or spirited'.

As Oades (2006, p. vii) explains: 'the observer may perceive and describe the potential problem as being one of [cannot sit still or cannot concentrate], of impulsivity, poor control of behaviour and emotional responses'. Through a process of observation, an interview and applicable testing, professionals then decide if attention is impaired, if response inhibition is poor, all towards making a diagnosis and

designing an appropriate treatment approach. As a categorical decision, it is required that a certain number of features be ‘ticked off’ when concluding with a diagnosis (Oades, 2006, p. vii).

There is however now recognition that observations should be formalised by rating the degrees of severity of the problem feature(s)...is the child more restless than I might expect a 6 year-old to be? How much more? Is there a little, a modest amount or quite a lot of the item concerned (Oades, 2006)?

Oades (2006, vii) believes a dimensional approach recognizes that ‘activity and attentional impairments are found, more or less, throughout the population’ and that a very good reason for using a dimensional rating approach is ‘to provide a much needed alternative to the categorical diagnoses provided by the World Health Organization and the American Psychiatric Association’.

### **2.1.2 PREVALENCE**

Prevalence rates of ADHD were estimated to occur in 3% to 7% of school-aged children, the majority being boys. Worldwide, its prevalence was considered approximately 5% (Flisher, Sorsdahl, Hatherill and Chehil, 2010). In their 2011 article *Advances in Understanding and Treating ADHD*, Antshel et al (2011, p.72) quote more recent studies placing ‘the figure closer to 7% to 8% of school-age children and 4% to 5% of adults’ with prevalence rates varying according to risk factors such as ‘age, male gender, chronic health problems, family dysfunction, low socioeconomic status, presence of a developmental impairment and urban living’.

Understanding ADHD in terms of prevalence rates requires acknowledging the majority of data consists largely of North America sources. There is little information relating to ADHD prevalence rates in Africa. In 2004 Meyer, Eilertsen, Sundet, Tshifularo and Sagvolden conducted a prevalence study within various language groups in South Africa using a teacher rating scale. The results of this study showed prevalence figures obtained were similar to those of Western countries.

The Hyperactivity/Attention Deficit Support Group of South Africa estimated that in 2004, 10% of all South African children may have characteristics associated with ADHD. No official statistics, however, on the prevalence of ADHD in South Africa are available (Snyman and Truter, 2010).



### 2.1.3 ETIOLOGY

A review of literature exploring ADHD and its possible causes still reflects much controversy. In their 2012 journal article *Practitioner Review: What have we learnt about the causes of ADHD?* Thapar, Cooper, Eyre and Langley, detail evidence indicating how genes, pre and perinatal risks, psychosocial factors and environmental toxins have all been considered as potential risk factors.

Focusing on literature published since 1997, their review critically considers those risk factors named above. The following conclusions, adapted from Thapar, et al (2012) are significant:

- No single risk factor can explain ADHD.
- Both inherited and non-inherited factors contribute to its cause.
- The effects of both inherited and non-inherited factors are interdependent.
- ADHD is familial and heritable. Studies of identical twins found that 80% to 90% of ADHD in both twins could be explained by genetic factors, and that ADHD occurs five to seven times more frequently in the families of persons with the disorder (Grantham, 1999).
- Under-activity in areas of the brain that control inhibitory response suggests a neurological link.
- ADHD can be the result of chemical disruptions to the prefrontal cortex or regions of the brain that connect to it. A lack of proper chemicals affects the frontal lobes, in such a way that they fail to properly inhibit emotional responses. This results in inappropriate cognitive or psychological responses, behavioural impulses, and reduced attention-monitoring processes.
- Research into the inherited and molecular genetic contributions to ADHD suggest an important overlap with other neurodevelopmental problems such as autistic spectrum disorders.
- Having a biological relative with ADHD, extreme early adversity, pre and postnatal exposure to lead and low birth weight/prematurity have also consistently been found as risk factors – none however are known to be causal.
- Associations between ADHD and a variety of environmental risks can, at present, be regarded as correlates. Future studies into environmental risk factors associated with ADHD need to go beyond assessing correlation and look for evidence of causal links. The table below depicts these risk factors.

**Table 2: Environmental risks that have been most commonly studied in relation to ADHD**

<b>Pre- and perinatal factors</b>	<b>Environmental factors</b>	<b>Dietary factors</b>	<b>Psychosocial adversity</b>
Maternal smoking, alcohol and substance misuse  Risk but not proven causal risk factor	Organophosphate pesticides  Risk but not proven causal risk factor	Nutritional deficiencies eg, zinc, magnesium Polyunsaturated fatty acids  Correlate not yet proven risk factor	Family adversity and low income  Correlate not yet proven risk factor
Maternal stress  Risk but not proven causal risk factor	Polychlorinated biphenyls  Risk but not proven causal risk factor	Nutritional surpluses eg sugar, artificial food colourings  Correlate not yet proven risk factor	Conflict / parent child hostility  Correlate not yet proven risk factor
Low birth weigh and prematurity  Risk but not proven causal risk factor	Lead  Risk but not proven causal risk factor	Low/high igG foods  Correlate not yet proven risk factor	Severe early deprivation  Risk, likely causal risk factor

Thapar, et al (2012)

## **2.2 ASSESSING APPROACHES TO TREATMENT**

Kaplan and Newcorn (2011, p.116) refer to ADHD as ‘the most frequently occurring child and adolescent psychiatric condition for which families consult a variety of medical specialists including paediatricians, family practitioners, psychiatrists, and neurologists, as well as non-physicians’. Left undiagnosed and untreated, ADHD negatively impacts on an individual’s ‘learning capacity, [their] family life, education, social interaction’ and may lead to depression and / or anxiety (Danciu, 2011, p.2968).

Danciu (2011, p.2968) writes: ‘In addition to its central traits, [ADD/ADHD] can lead to a series of associated, secondary traits, such as: disorganization; poor social relations with [siblings] and children of the same age; aggressive behaviour; low self esteem and deficient self-knowledge; self-stimulation behaviour; daydreaming and absentmindedness; coordination deficits; memory problems [and] persistent obsessive thoughts’.

Despite there being overall progress in terms of understanding ADHD, diagnosis and the assessment of cause, much controversy around the disorder still exists. The existence of ADHD, whether it can be reliably diagnosed and how it should be treated are topics of much debate.

The benefits of identifying and treating ADHD early have long been recognized. Implementation of chosen interventions can minimize negative projections and reduce the need for additional remediation. Davis and Williams (2011, p.145) believe interventions ‘should be based on sound evidence to ensure that the safest and most effective treatments are implemented and that the treatments do not impede optimal developmental progress unnecessarily... in children, there is [however] a delicate balance between providing optimal treatment and minimizing [the] negative effects of those interventions’.

Given the potential for adverse outcomes, effectively treating ADHD is critical. The array of available literature on the treatment of ADHD expands across three general approaches: 1) A purely pharmacological approach (the use of prescription medication); 2) A behavioural/psycho-social approach (encompassing nutritional interventions, biofeedback, remedial therapy, homeopathy, occupational therapy and numerous psychological interventions); and 3) A combined approach where both use of prescription medication and behavioural/psychosocial therapies are incorporated. Available treatment options include non pharmacological management as in behaviour therapy, psychological therapy, complementary and alternative medicines (CAMs) and dietary modifications, as well as pharmacological treatment management using prescription stimulants, non-stimulants and other medications such as antidepressants and some antipsychotics (van der Westhuizen, 2010, p. 11).

There have been many studies attempting to determine which treatment approaches are most effective (Hamrin, McCarthy and Tyson, 2010; Snyman and Truter, 2010 and Doggett, 2004). Davis and Williams (2011, p.149) believe further research is needed on ‘all types of intervention[s], including combinations of interventions’. They view research into ‘the long-term outcome and safety of treatment interventions and their impact on the developing brain of preschool children with ADHD’ as important.

In addition to this Davis and Williams (2011, p.149) motivate for longitudinal studies seeking to understand ‘the risk–benefit ratio of potential interventions as it is clear that brain development continues beyond childhood and is influenced by both positive and negative events’.

To date there is no agreement in the literature as to an overall effective ADHD treatment. Jackson and Peters (2008, p.2726) are of the opinion that views as to what constitutes appropriate treatment for ADHD are polarized. They explain that on one end of the spectrum ‘are those who believe that stimulant medication is the most efficacious and appropriate treatment for ADHD’ with those at the other end supporting various alternative approaches, believing stimulant medication to be overprescribed. The various available treatment approaches (mentioned above) all show limitations with respect to outcomes. In the assessment of these approaches, Brinkman and Epstein (2011, p.47) state ‘the most widely evaluated approach to treating ADHD has been the use of different types of medications, particularly stimulant medications’.

Jackson and Peters (2008, p.2726) describe the use of stimulants as ‘contentious’. They refer to literature detailing several concerns with stimulant medication. These concerns are listed as ‘ethical issues associated with long-term stimulant medication use in young children, the nature of any short or long-term effects relating to [stimulant] use, widely held beliefs that drugs are used as a means of control to benefit carers rather than children themselves’ and various fears and stigmas associated with their administration (Jackson and Peters, 2008 p.2726).

According to Coghill (2003), there has been more research into the use of medication for the treatment of ADHD than into any other area of child and adolescent psychopharmacology - ‘it is still the case that about half of all papers published concerned with psychoactive medication and children are on the treatment of ADHD’ (Coghill, 2003, p.87). In their 2011 article, *Medication Treatment for Attention Deficit Hyperactivity Disorder*, Ryan, Katsiyannis and Hughes refer to ADHD as the most commonly diagnosed psychiatric disorder among school-age children. They confirm that although doctors have prescribed medications to help manage behaviours such as hyperactivity, impulsivity, and inattention for more than a decade, today there is increasing consensus that ADHD is a biologically based disorder, and that medication is now considered the first line treatment (Ryan et al, 2011).

Although drug free alternatives such as cognitive/behaviour modification therapy, educational interventions, biofeedback and diet manipulation are increasing in popularity, it is now generally accepted that medication, in the form of stimulants, plays an important role in the management of ADHD. Vitiello (2008, p.666) writes that ‘while the ultimate decision of which treatment modality (psychosocial, pharmacological or combined and in the case of pharmacotherapy) to use first rests with the clinician and the patient, there is now ample evidence that stimulants are the most effective treatment for decreasing symptoms of ADHD’.

In their 2011 journal article, Wender, Reimherr, Marchant, Sanford, Czajkowski and Tomb reported on their study examining ‘the efficacy of methylphenidate in the long-term treatment of ADHD in adults on both ADHD symptoms and, economic, educational, vocational, social, extended family, marital, and parental functioning’ (2011, p.36). Highlighting a decrease in symptom severity, life changing improvements in social functioning and no drug abuse or tolerance, the authors concluded that ‘a long-term trial of methylphenidate in adults with ADHD produces extremely large, life-altering changes in symptoms and in work and social functioning’ (Wender et al, 2011, p. 43).

### **2.2.1 PSYCHO-STIMULANT USE**

Chelarua, Yanga and Dafnya (2012, p. 8) state ‘methylphenidate is the most widely used drug in the treatment of ADHD. Methylphenidate (known also as MPH, Ritalin, Concerta, Metadate, or Methylin) is a psycho-stimulant drug approved for the treatment of ADHD. Methylphenidate was first synthesized in 1944 and was identified as a stimulant in 1954 (Meier, Gross and Tripod, 1954). It is the most commonly prescribed psycho-stimulant and works by increasing the activity of the central nervous system to produce effects such as increasing or maintaining alertness, combating fatigue, and improving attention. Stimulant medication serves to ‘reduce the severity of some behavioural problems, thus allowing children to engage more appropriately with those around them’ (Jackson and Peters, 2008 p.2726).

In addition to methylphenidate, Atomoxetine (Strattera), a noradrenaline reuptake inhibitor, is also used in South Africa as a pharmacological treatment for ADHD. Strattera is a non-stimulant and appears to have less severe effects on appetite and sleep than methylphenidate. It has however been known to produce somewhat more nausea or sedation. As a treatment, ‘peak efficacy occurs between two to six weeks after initiation but can take up to eight weeks which is in contrast to the stimulants, which give a

rapid response' (van der Westhuizen, 2010, 17). Table 3 on the page that follows provides a summary of pharmacological preparations indicated for the treatment of ADHD in South Africa.

**Table 3: Pharmacological preparations indicated for ADHD in South Africa.**

Drug	Brand	Strength	Dosage instructions	Additional information
Methylphenidate HCl	Concerta ER tablets	18mg 36mg 54mg	<b>New patients</b> 18 mg once daily. Adjust in 18 mg increments at weekly intervals to max 54 mg/d for children 6–12 yrs. 72 mg/d for adolescents 13–18 yrs.  <b>Patients currently taking methylphenidate:</b> 18 mg od for pts taking 5 mg tds, 36 mg od for pts taking 10 mg bd-tds, 54 mg od for pts taking 15 mg bd-tds, 72 mg od for pts taking 20 mg bd-tds	Not for children under 6 years. Administer once daily in the mornings. Effects shown to be present 12 hours after dose. Swallow whole and never crush, chew or divide. Non-absorbable tablet shell may be seen in stool. Longer acting stimulants offer greater convenience, confidentiality, and adherence with single daily dosing but may have greater problematic effects on evening appetite and sleep.
Methylphenidate HCl	Methylphenidate HCl-Douglas	10mg	Initially 5 mg before breakfast and 5 mg before lunch with gradual weekly increments of 5–10mg to max 60 mg/d. Admin to a total daily dose in divided doses. Dose in terms of body wt: usual 0.25 mg/kg/d, double each week to 2mg/kg. Consider short-act trial dose at bedtime if rebound effects experienced.	Short-acting stimulants often used as initial treatment in small children (< 16 kg) but have disadvantage of bd-tds dosing to control symptoms throughout the day.
Methylphenidate HCl	Ritalin tablets	10mg	Initiate in small doses with gradual weekly increments. Daily dose over 60 mg not recommended. Discontinue if no improvement observed after appropriate dose adjustment over one month.	Short-acting stimulants often used as initial treatment in small children (< 16 kg) but have disadvantage of bd-tds dosing to control symptoms throughout the day.
	Ritalin LA capsules	20mg 30mg 40mg	Recommended start dose 20 mg. Dose to replace standard formula: 20 mg LA od to replace 10 mg bd, 30 mg LA od to replace 15mg bd, 40 mg od to replace 20 mg bd. In case of other regimens use clinical judgment.	Administer once daily in the morning. Do not crush or chew or divide. Contents may be sprinkled on a small amount of soft cold food and swallowed immediately. Longer acting stimulants offer greater convenience, confidentiality, and adherence with single daily dosing but may have greater problematic effects on evening appetite and sleep.
Atomoxetine HCl	Strattera capsules	10mg 18mg 25mg 40mg 60mg	<b>Child and adolescent &lt; 70 kg:</b> Initial total daily dose 0.5 mg/kg. Maintenance dose: initial dose for 7 days before upward titration according to clinical response. Recommended maintenance dose: 1.2 mg/kg/ day. No add benefits seen with higher dose.  <b>Child and adolescent &gt; 70 kg:</b> Initial total daily dose 40 mg. Maintenance dose: initial dose for 7 days before upward titration according to clinical response. Recommended maintenance dose: 80 mg. No additional benefits seen with higher dose.	If dose missed take ASAP but prescribed total daily dose not to be exceeded in any 24 hours. Consider if active substance abuse or severe side effects of stimulants (mood lability or tics) give every morning or bd (effects on late evening behaviour). Monitor closely for suicidal thinking or behaviour, clinical worsening, or unusual changes in behaviour.

Wolraich, Lindgren, Stromquist, Milich, Davis and Watson in their study *Stimulant Medication Used by Primary Care Physicians in the Treatment of ADHD* (1990) found that 80% of children diagnosed with ADHD were treated with stimulant medication. In treating ADHD, psycho-stimulants in particular are now readily available and are being prescribed with increasing frequency (Christensen-Szalanski and Northcraft, 1985). According to the Reiff (2011) stimulants are the most frequently prescribed medications for ADHD - paediatric groups endorse the use of stimulants as first line therapy in most children with ADHD aged 6 – 12 years, estimating that 80% of these children will respond to stimulants.

The widespread use of stimulant medication as a treatment has generated significant controversy. Psycho-stimulants prescribed for ADHD exert their effects in the nervous system ‘by altering the way in which the neurotransmitters function’ (Doggett, 2004, p.74). Although concentration and attention are improved, these drugs may have both unpleasant and / or unwanted side-effects. The most common side effects of methylphenidate are nervousness, insomnia and short term weight loss (due largely to a decrease in appetite). Other adverse reactions include: abdominal pain, appetite loss, anxiety or panic attacks, blood pressure and pulse changes (both up and down), cardiac arrhythmia, increased sweating, dizziness, dysphoria or euphoria, headaches, nausea, palpitations, and dryness in the mouth (www.drugs.com). In addition to these short-term adverse effects, Doggett (2004, p.70) states ‘critics have questioned the long-term safety and efficacy of chronic pharmaceutical use’. The effects of long-term methylphenidate treatment, particularly on developing children with ADHD, are the subject of much study and debate.

Although the safety of short-term methylphenidate use in clinical trials has been relatively well established, repeated and long-term use of psycho-stimulants is less clear. In this respect, data is limited: There are no guidelines relating to the specifics of withdrawal for discontinuing long-term use of stimulants and the relationship between long-term use of medication during childhood and future risk of substance abuse is also an area of concern (Ashton, Gallagher and Moore, 2006).

In their naturalistic observational study evaluating ‘410 real-life patients treated with stimulants and assessed systematically over several years’, Powell, Thomsen, Frydenberg and Rasmussen (2011, p.439), relay the following important findings: ‘stimulant dosages are dynamic over time and depend on individual factors’. These individual factors influence outcome - patients with ADHD being treated with stimulants should therefore be individually monitored and have dosages adjusted accordingly. Comorbidities, age at start and treatment needs over time are evidence as to the diversity of ADHD, tailoring individual treatment schedules requires individual factors be taken into account.



Van der Westhuizen (2010, p. 20) outlines the following factors to consider when assessing treatment options:

- ‘No single treatment is the answer for every patient – a number of factors are involved in determining the best treatment for the individual.
- Drug treatment is not recommended as first line in children under the age of five.
- If using methylphenidate the choice of preparation needs to be considered: modified-release preparations are convenient due to their pharmacokinetic profile, improving adherence, reducing stigma (drug does not need to be taken at school); and immediate-release preparations are preferred if more flexible dosing is required or during initial titration to determine correct dosing levels.
- Co-morbidities must be treated.
- It is recommended by manufacturers that drug treatment is suspended every one to two years so that the child’s condition can be reassessed.
- Patients not continuing with therapy need to be given appropriate withdrawal strategies’.

## **2.3 WITHIN A SOUTH AFRICAN CONTEXT**

There is an increased focus in the lay and medical press in South Africa on the use of stimulants. The pharmaceutical intervention of ADHD is significantly under-researched in South Africa and studies that are available on ADHD are limited. Although sales figures are available for different drugs, no comprehensive South African database exists from which methylphenidate prescribing patterns, particularly over extensive time periods, can be studied. No computerized medication records are available for the state or public sectors, and very few private sector databases containing comprehensive diagnostic information linking specific medicine items to a specific diagnosis, exist.

In her 2009 study, *Prescribing of methylphenidate to children and adolescents in South Africa: A pharmacoepidemiological investigation*, Ilse Truter sought to analyze the prescribing of methylphenidate to patients aged 18 years and younger in the private health care sector. This study attempted to contribute to the limited literature on the prescribing of methylphenidate in South Africa. Data for a one-month period containing medicine records for 355 998 patients in 2004 was obtained from one of the large medical aid administrator.

The results showed a total of 66 450 medicine items were prescribed to 34 733 patients aged 18 years and younger in that month. A total of 1028 patients received prescriptions for methylphenidate.

The average age of these patients was 10.87 years. 63.14% of these prescriptions were for children between seven and twelve years of age. 48.87% of these prescriptions were for long-acting methylphenidate in 20 mg, 30 mg and 40 mg capsules. The average prescribed daily dose for methylphenidate was 19.27mg. The highest average percentage of methylphenidate prescriptions was in the Western Cape (2.58%), and the lowest in the Northern Cape (0.63%) (Truter, 2009, p.413).

Tables 4 and 5 below illustrate additional results for reference:

**Table 4: Percentage prescribing frequency of methylphenidate in South Africa's nine provinces.**

<b>Province</b>	<b>Percentage (%)</b>
Eastern Cape	1.98
Free State	1.16
Gauteng	1.67
KwaZulu-Natal	2.10
Mpumalanga	1.66
North-West Province	1.38
Northern Cape	0.63
Northern Province	1.22
Western Cape	2.58
<b>All Provinces</b>	<b>1.81</b>

Truter (2009, p.416)

**Table 5: Areas with the most methylphenidate prescriptions within South Africa's nine provinces.**

Rank	Area	Percentage (%)		Total		All Products	
		Acute (n=858)	Chronic (n=343)	Number (n=1201)	%	Number (n=66 405)	%
1	Pretoria	10.02	12.54	129	10.74	7646	1.69
2	Johannesburg North	10.61	9.33	123	10.24	5270	2.33
3	Bellville	7.34	9.91	97	8.08	2749	3.53
4	Johannesburg	4.78	7.58	67	5.58	4161	1.61
5	Johannesburg CBD	5.01	3.21	54	4.50	3295	1.64
6	Durban	3.69	4.08	48	4.00	2048	2.95
7	Port Elizabeth	4.43	2.92	48	4.00	1628	2.95
8	Edenvale	4.20	2.33	44	3.66	2413	1.82
9	Pietermaritzberg	2.68	5.54	42	3.50	1109	3.79
10	Cape Town	3.15	3.79	40	3.33	2025	1.98
11	Alberton	2.45	2.33	29	2.41	1546	1.88
12	Kempton Park	2.45	2.04	28	2.33	1946	1.44
13	Klerksdorp	1.98	1.75	23	1.92	972	2.37
14	Nelspruit	2.33	0.87	23	1.92	752	3.06
15	Stellenbosch	1.63	2.04	21	1.75	668	3.14
16	Benoni	1.40	2.33	20	1.67	1266	1.58
17	Pinetown	1.17	2.92	20	1.67	804	2.49
18	Bloemfontein	1.98	0.58	19	1.58	1308	1.45
19	East London	1.86	0.58	18	1.50	848	2.12
20	Bluff	1.75	0.29	16	1.33	507	3.16

Truter (2009, p.416)

In addition to the above mentioned statistical findings, results confirmed Methylphenidate is the psycho-stimulant that is most frequently prescribed in the management of ADHD in South Africa. It is also considered to be the first-line medication in its treatment.

Positive experiences from prescription treatment include an improvement in ADHD symptoms, school performance and family relationships, as well as reduced levels of parenting stress. Identified costs include several side effects such as actual or perceived social stigma, a possible lack of response, the fear of addiction, and the fear of long term medication changing the child's personality (Hamrin et al, 2010).

According to Reiff (2011), with effective stimulant medication treatment, children with ADHD are better able to manage academic work and social interaction, attend to behaviour modification techniques, and follow rules. Reiff (2011) advocates that by helping a child focus, stimulants lay the groundwork for being able to respond better to behaviour management techniques, academic instruction, and other attentional demands - research has shown that such other treatments are more likely to work if the child is also taking stimulants (Reiff, 2011).

Prescription rates of psycho-stimulants, particularly methylphenidate, have significantly increased – this has raised public health concerns regarding the frequency and appropriateness with which these medications are prescribed (Truter, 2009).

The increase in the prescribing and use of stimulants over the last couple of decades has led to concerns in the media and among parents about whether stimulants are being overprescribed for children with ADHD. According to Reiff (2011), most of the increase in stimulant medication use is likely to stem from better recognition and diagnosis of ADHD (including a greater awareness of ADHD in girls) and from the trend for children to be treated for longer periods, sometimes through to adulthood.

There is still debate as to whether ADHD is over diagnosed or under-diagnosed (Reiff, 2011). Before embarking on a treatment course, accurate diagnosis is therefore important. Reiff (2011) believes one must first weigh up the pros and cons of choosing medication as part of the treatment plan for ADHD and that the more educated individuals are about the medication process, the better prepared they will be to make an informed decision.

One of the most difficult decisions facing parents of ADHD children is planning and delivering a treatment package – should it be exclusively a pharmacological approach, an alternative therapy approach or a more-expensive and time-consuming package of combined psychosocial and pharmacological treatments? Diverse and conflicting opinions about the diagnosis and treatment of this disorder leave parents with difficult decisions to make in terms of how to best treat their ADHD child.

## **2.4 TREATMENT DECISION MAKING**

Research examining the experiences of parents raising children with ADHD indicates that parents often endure a sense of fear in having to administer drugs to their children for behaviour change purposes (Klasen, 2000). In addition to this, Hamrin et al (2010) believe families' attitudes, beliefs and perceptions about psychiatric illness and treatment play a large role in medication treatment decisions. Research examining the factors that mediate a parents decision to use psycho-stimulant medication in treating ADHD is a significantly under researched domain.

In a study investigating factors that mediate treatment adherence to psycho-stimulant therapy in treating ADHD, Jasmin Kooverjee (2006) relayed several interesting findings. Included in these are the following:

- Ninety percent of parents from two parental groups interviewed were advised to seek professional treatment for their children by teachers due to the child's poor scholastic performance, behavioural problems or motor skill deficits – within this, a portion of these parents felt they had been forced to place their child on psycho-stimulants due to pressure from their child's teacher;
- Due to homeopathic medication not being covered by medical aid, parents felt forced to use psycho-stimulants which are covered by medical aids – with homeopathic treatments costing the same, if not more than prescription medication yet not covered by medical aid, financial pressure meant opting for that which medical aid did cover;
- Parents all agreed that it was necessary to have adequate information from all practitioners as well as other sources prior to making a decision to place a child on medication;
- Advice parents would offer to other parents whose children were diagnosed with ADHD was to seek assessment from a competent psychologist and pediatrician, to first try environmental modifications (e.g. changing diet and structuring the home environment); and, as a last resort, to consider use of psycho-stimulants and that

- Adequate and comprehensive psycho-education of parents is required, specifically regarding the etiology of ADHD, core symptoms of the disorder, the type and function of available psycho-stimulants, their side-effects and importantly alternative forms of treatment.

In their 2011 article *Treatment planning for children with attention-deficit/hyperactivity disorder: treatment utilization and family preferences*, Brinkman and Epstein review literature examining patient and parent treatment preferences. Their summary of qualitative and quantitative research assessing treatment preferences concludes that ‘after a child is diagnosed with ADHD, a variety of factors influence the initial selection of treatment modalities that are utilized’ (Brinkman and Epstein, 2011, p.52).

It is detailed that a process of ‘optimizing care, similar to a family/self-management process described for other chronic conditions’, is undertaken (Brinkman and Epstein, 2011, p.52). It is explained that preferences ‘are initially shaped by a parent’s beliefs about the nature of their child’s problems and by information (and misinformation) received from a variety of sources, including social networks, the media, and health care providers’ (Brinkman and Epstein, 2011, p.52).

Subsequent to this, initial preferences ‘become further informed by personal experience with various treatment modalities. Over time, treatment plans are revisited and revised as families work with their health care team to establish a treatment plan that helps their child achieve goals while minimizing harms and costs’ (Brinkman and Epstein, 2011, p.52).

In an effort to better understand how parents make treatment decisions for their child with ADHD, Brinkman et al (2009) conducted a qualitative study incorporating 52 parents in focus groups where they were required to answer questions about decision-making, information sharing, and sources of conflict and uncertainty.

Brinkman et al (2009) describe the context of decision making as one containing many parent stressors. Included in these are: self doubt, daily struggles both at home and at school, parental conflict with one another, self blame, having parenting skills challenged and carrying the emotional burden of having to make a decision. In terms of factors influencing decisions to initiate medication, Brinkman et al (2009) presented these as a weighing up of factors that supported initiation of medication and factors that delayed initiation of medication.

Factors included in supporting initiating medication were: parents recognizing and accepting their child has a level of impairment, the identification of a problem by a teacher, accepting the diagnosis, having a positive relationship with the family doctor, experiencing extended family support and failure of other, alternative approaches. Included as factors delaying initiation of medications were: denial of a problem, poor parent / teacher communication, lack of confidence in the diagnosis, concerns regarding side effects, lack of support from friends and family members, stigma, negative social media reports and a desire not to rely on medication as a solution (Brinkman et al, 2009). In addition to the above, Brinkman et al (2009) recognize the decision making process as one that is regularly revisited where parents experience ongoing doubt and uncertainty regarding their decision to medicate.

According to Brinkman et al (2009, p.580) ‘choices are often made under stressful conditions and influenced by a variety of factors where decisions about medication use for children with ADHD ‘are made and frequently revisited by parents...striking a balance between benefits and concerns is an ongoing process that is often informed by contrasting time on and [time] off medication’.

Jackson and Peters (2008, p.2726) believe it ‘is important that health professionals have a greater awareness of the experiences and concerns of [parents] in relation to the use of stimulant medication for ADHD’. In their article *Use of drug therapy in children with attention deficit hyperactivity disorder (ADHD): maternal views and experiences*, findings show the decision to medicate their child (or not) was one that was made very carefully as a deep commitment to doing the best by their child was significant... although there was acceptance that medication had some benefits, at what cost were these benefits – participants expressed reservations about the use of daily medication.

Results of this study show that ‘decisions around the use of stimulant medication for children with ADHD are difficult’. Themes of ambivalence and confusion; the influence of the media; deciding against medication and deciding for medication emerged (Jackson and Peters, 2008, p.2725).

Jackson and Peters (2008, p.2731) believe ‘it is important that parents are able to access accurate information and have the opportunities to raise concerns and express their feelings’ in deciding on a treatment approach for their ADHD child.

In their exploratory, descriptive study using focus groups to examine parental evaluations of treatment approaches to ADHD and the congruence of these evaluations with professional practice guidelines, Bussing and Gary (2001) confirmed that parental accounts uniformly depicted stimulant use as a difficult treatment to consider and accept for their children. Additional findings indicated that professional guidelines and parent ADHD treatment evaluations were only partially congruent, with the greatest discrepancy being in the role of stimulants. The authors suggest ‘increased provider-parent communication concerning medications might improve adherence and treatment outcomes’ (Bussing and Gary, 2001, p.223).

In their 2010 study, *Parent Perspectives on the Decision to Initiate Medication Treatment of Attention-Deficit/Hyperactivity Disorder*, Coletti, Pappadopulos, Katsiotas, Berest, Jensen and Kafantaris analyzed focus group data which identified social, cognitive, and affective influences on treatment decision making. Findings suggested that parent attitudes need to be assessed comprehensively at the initial evaluation to aid the development of psycho-education and a more careful consideration as to how parents interpret and respond to information.

In an unpublished social work thesis titled: *Children with attention deficit hyperactivity disorder needs and experiences of parents/caregivers receiving services from a public sector hospital* by Matthias (2012), it was found that participants did not have sufficient knowledge of the comprehensive treatment plans available in the management of ADHD. In addition to this, health care professionals failed to engage in mutual decision making with participants related to ADHD treatment and they neglected to address the concern participants had regarding their children. A further finding was that the referral process to health professionals was inconsistent. Based on the findings, the recommendations following this research included the need for more comprehensive medical and psychosocial support for participants; the need for health care providers to address the limited knowledge base of participants with regard to the nature and causes of ADHD and the use of medication. Matthias (2012) believes this could be achieved through participant education on the disorder where ADHD is managed in a more collaborative and co-ordinated manner at health care facilities through an actively interdependent team.



### 2.4.1 DECISION MAKING THEORY

In their article, *Parents' Dilemmas in Choosing Empirically Supported Treatments for Child ADHD*, Yuanyuan Jiang and Charlotte Johnston (2010, p.8) place significant value on recognizing and supporting parents with the challenges they face in their decision making regarding a treatment plan. They believe it necessary to be sensitive to 'the obstacles that parents' foresee encountering in using behavioural management or medication treatments, or both, while also remaining cognizant that these perceived obstacles may not reflect what parents will actually experience'.

Considering the fact that no treatment approach to ADHD is perfect or without drawbacks, opposing and conflicting attitudes of acceptability and effectiveness are grappled with in the decision making process.

Treatment decision-making is a process which presents a family with a unique journey in which both the assessment and exploration of alternatives is required. Theoretical considerations offer us an aid towards understanding and appreciating this experience. Placing treatment decision-making within a theoretical framework is fundamental towards gaining an insightful comprehension of influences on an individual's behavioural intention.

Judgment and decision making research is broadly separated into two areas: those focusing on judgments and those focusing on decisions. A decision can be defined as 'a commitment to a course of action'. Research on decision making is guided by a focus on understanding how people choose a course of action and more specifically, how people decide what to do when they have conflicting goals and when the outcome is uncertain. A judgment can be defined as 'an assessment or belief about a situation based on available information'. Research in this area is more focused on understanding how people integrate multiple sources of information to arrive at an understanding or judgment of a situation (Newell, Lagnado and Shanks 2007, pp.19-20).

Decision making theory has its roots mainly in economics, statistics, and operations research and only recently has received attention from psychologists. The past forty years have seen widespread applications of these theories across a variety of disciplines. From a psychological perspective, it is necessary to examine individual decisions within the context of needs, preferences an individual has and their values.

In examining decision making processes, van der Heide, Vrakking, van Delden, Looman and van der Maas (2004) believe that for many, decision making is influenced by empirical evidence where evidence includes results of clinical trials in which the effect of an intervention has been assessed in a well-defined patient group. ADHD treatment decisions need to take into account the severity of the symptoms, the child's coping abilities, the availability of other treatment interventions and related financial implications. While medical teams can provide parents with necessary information, supported by documented evidence, Cyne Johnston, Durieux-Smith, Fitzpatrick, O'Connor, Benzies and Angus (2008) argue the actual decision-making process is usually invisible to the professionals.

According to Newell et al (2007) our decisions can be greatly influenced by the way in which information is presented. Subtle differences in the way numbers are represented or options are displayed can affect the decision made.

#### **2.4.2 NORMATIVE / PRESCRIPTIVE APPROACHES**

Normative / prescriptive theories of decision making are complemented by empirical research that shows how people actually make decisions. This research demonstrates that people approach decision making as a selective search, using a means-ends analysis as a principal guiding technique. From this theoretical perspective, the analysis of individual decisions is concerned with the logic of decision making and rationality and the ultimate choice it leads to.

It is concerned with identifying the best decision to take, assuming an ideal decision maker who is fully informed, able to compute with perfect accuracy, and fully rational. The most influential explanatory concept in the analysis of decisions within this approach is the Subjective Expected Utility (SEU) of available alternatives. In specifying how decisions should be made, SEU involves organizing decisions or choices into probabilities (beliefs) and preferences (values or utilities) and establishing a statement or rule combining and complementing ones probabilities and preferences. This is however based on an underlying assumption that the probability of all relevant variables can be provided by the decision makers (Simon, 1996; Newell et al, 2007 and Stein, 2005).

The real world of human decisions is not one of ideal rationalizations. Limits to ideal rationality are imposed by the complexity of the world in which we live, by the incompleteness and inadequacy of human knowledge, by the inconsistencies of individual preferences and beliefs and by the conflicts of

values among people and groups of people. It is well supported that people rarely conform to the expectations of rational decision making (Goldstein, 2007; Eysenck, 2004).

### **2.4.3 DESCRIPTIVE APPROACHES**

Cognitive overload as a result of combining substantial amounts of relevant information about probabilities and values provokes a need for simplification. It can then be expected that people employ decision making processes that require less cognitive effort than normative approaches such as SEU-theory. Real life decision making simply cannot practically encompass an exhaustive analysis of probabilities and preferences and as the limits of rationality are clear. Decision making theory has shifted to considering how people's thought processes shape the choices they are required to make - an attempt to describe what people will actually do (Eysenck, 2004).

Descriptive approaches to decision making are concerned essentially with how people make sense of the decisions faced and how they apply approximate techniques to handle complexities that cannot be handled exactly. Descriptive approaches have increased insight into the cognitive processes underlying decision making. Their focus is primarily on the information processing strategies that people use when making judgments or decisions and the role of emotions in the decision-making process. When faced with a decision, people aim for an acceptable solution - not necessarily the best possible solution (Eysenck, 2004). Descriptive approaches regard the decision making process as a continuous one, integrated in the individual's interactions with the environment – where it is both a reasoning and an emotional process which can be rational or irrational, based on assumptions that are either clearly expressed or implied. Finding the underlying basis of human decision making is difficult. People cannot always provide realistic accounts of how they make a decision, particularly when there is uncertainty. It still remains as an overwhelming and challenging task to incorporate all considerations into an encompassing theory of decision making, particularly one related to medical treatments.

### **2.4.4 SHARED DECISION MAKING**

Shared decision making is an approach where doctors and patients communicate together using the best available evidence when faced with the task of making treatment decisions. Patients are supported in exploring possible attributes and consequences of various options in an attempt to arrive at an informed preference - making a decision about treatment (Frosch and Kaplan, 1999). It is an approach encompassing respect for patient autonomy and it is a desired, ethical and legal process (Elwyn, Edwards, Kinnersley and Grol, 2000; Charles, Gafni and Whelan, 1997).

Shared decision-making is increasingly advocated as an ideal model of treatment decision-making (Frosch and Kaplan, 1999). Charles et al (1997) believe that to date, the concept has been both poorly and loosely defined. In implementing shared decision making, Charles et al (1997) suggest a criteria as follows: (1) that there are at least two participants involved (the physician and the patient) as a minimum; (2) that both parties share information; (3) that both parties take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to be implemented.

There is increasing interest in interventions that help patients become involved in decision-making about healthcare choices (Frosch and Kaplan, 1999). Elwyn et al (2008) describe 'decision aids' as interventions that provide those making decisions with information related to the nature and probabilities of various options. These aids may be in the form of paper-based hand outs, videos and / or web links which may be given to patients before, during or after consultations with health professionals. Information they relay should include details on the clinical condition; outcome probabilities tailored to personal risk factors; descriptions of others' experiences; and guidance in the steps of decision-making and communicating with others.

In their 2008 study *An Assessment of Parents' Decision-Making Regarding Paediatric Cochlear Implants*, Cyne Johnston et al incorporate one particular aid that provides a process to facilitate shared decision making - the Ottawa Decision Support Framework (ODSF). This framework is appropriate for decisions that (a) are stimulated by a new circumstance, diagnosis, or developmental condition, (b) require careful deliberation because of the uncertain and/ or value-sensitive nature of the benefits and risks, and (c) need relatively more effort in the deliberation stage than the implementation stage.

The decision parents are required to make in using psycho-stimulants in treating ADHD meets each of these criteria. The ODSF depicts how a family's decisional needs and decisional qualities influence each other. Decisional needs include (a) elements of the decision, such as timing, stage, and learning, (b) decisional conflict, (c) knowledge and expectations, and (d) values.

The ODSF is however relatively linear in its approach and does not adequately consider the numerous influences, parental cognitions, treatment perceptions, attitudes and beliefs that intertwine in deciding on treatment for an ADHD child. Individual level theories offer us a better understanding of these factors in exploring treatment decision making.

#### **2.4.5 THE HEALTH BELIEF MODEL**

The Health Belief Model (HBM) was one of the first, and remains one of the best known social cognition models (Janz and Becker, 1984). Developed by Irwin Rosenstock, it is a health behaviour change and psychological model for studying and promoting the uptake of health services (Rosenstock, 1966).

Originally, the model was designed to predict behavioural response to the treatment received by acutely or chronically ill patients, but in more recent years the model has been used to predict more general health behaviours (Glanz, Lewis and Rimer, 2002). The HBM was one of the first models that adapted and applied theory from the behavioural sciences to health problems (Glanz, 1999). In the 1970's and 1980's the model was further developed where amendments to the model were made to accommodate evolving evidence generated within the health community regarding the role of knowledge and perceptions in personal responsibility and decision making (Glanz et al, 2002).

This model proposes that following perceptual factors influence health behaviours (Jiang and Johnston, 2010):

- Perceived susceptibility (an individual's assessment of their risk of getting the condition)
- Perceived severity (an individual's assessment of the seriousness of the condition, and its potential consequences)
- Perceived barriers (an individual's assessment of the influences that facilitate or discourage adoption of the promoted behaviour - perceptions of potential difficulties or obstacles to performing the action chosen)
- Perceived benefits (an individual's assessment of the positive consequences of adopting the behaviour).

The HBM suggests that before an individual takes action, the individual must first decide that the behaviour creates a serious problem and that there is susceptibility to health harm. Following this, the individual must recognize that moderating or ceasing the behaviour would be beneficial (Gorin and Arnold, 1998).

The HBM suggests that an individual's belief in personal threat together with their belief in the effectiveness of the proposed behaviour will predict the likelihood of the individual initiating that behaviour (Petersen, Bhana, Flisher, Swartz and Richter (eds), 2010),

The HBM is based on the understanding that a person will take recommended action if there is the belief that a negative outcome can be avoided, if suggested recommendations will have a positive outcome and if that person feels they can successfully follow through with the recommended health action. Perceived barriers and / or the potentially negative aspects of a particular health action may act as obstacles to undertaking the recommended behaviour. Often individuals consciously or unconsciously engage in a cost benefit analysis, where the individual weighs the expected effectiveness of the action against perceptions that it may be expensive, dangerous (medication having severe side-effects), or unpleasant - difficult, upsetting, inconvenient and / or time consuming (Gorin and Arnold, 1998; Petersen et al, 2010).

The HBM therefore focuses on two related appraisal processes, the threat and the behavioural response to that threat. Threat appraisal involves consideration of both the individual's perceived susceptibility to negative consequences and the anticipated severity. Behavioural evaluation involves consideration of the costs and benefits of engaging in behaviours likely to reduce the threat (Glanz et al, 2002).

The HBM helps explain why individual patients may accept or reject preventative health services or adopt healthy behaviours. The HBM suggests that individuals will respond best to recommendations about health promotion when the following four conditions for change exist:

- The person believes that he or she is at risk should behaviour not change.
- The person believes that the risk is serious and the consequences of developing the condition are undesirable.
- The person believes that the risk will be reduced by a specific behaviour change.
- The person believes that barriers to the behaviour change can be overcome and managed.

The HBM is a framework for motivating people to take positive health actions using the desire to avoid a negative health consequence as the primary motivation. Appropriate fear-based messages are incorporated to facilitate susceptibility and severity (Glanz et al, 2002).

In addition to the above, the HBM considers factors which prompt action, understanding behaviour to be triggered by a 'cue to action' where health-related decisions are triggered by environmental cues (Petersen et al 2010, p. 22).

Closely linked to this is the proponent that motivation to change behaviour is the result of an individual feeling sufficiently threatened by their behaviour and recognising an ability to behave differently. Further extensions on this model incorporated the concept of self-efficacy – the perception that one has the ability to successfully perform an action (Petersen et al 2010).

Later versions of the model added an additional dimension, the individual's motivation or readiness to be concerned about health matters. This dimension has the potential to be greatly affected if defense mechanisms (such as denial as to the existence of a problem) lead to irrational thinking and unwillingness to accept the suggested treatment regime (Gorin and Arnold, 1998).

Adopting the HBM as a theoretical framework has some specific strengths. Included in these are that its common-sense constructs are straightforward to assimilate and apply, making the theory easily understood by non academics. In addition to this, the HBM has focused research attention on psychological prerequisites of behaviour that are modifiable. Also, the HBM makes testable predictions - large health threats for example might be offset by perceived costs and small health threats by large benefits (Glanz et al, 2002, Gorin and Arnold, 1998).

Despite the identified strengths of the HBM, some significant limitations need to be recognized. Important limitations are that the common-sense framework has a tendency to over-simplify health-related decisional processes. Closely related to this is that the theoretical components comprising the HBM are broadly / generally defined and may not necessarily be strictly comparable to all circumstances. In addition to this, the HBM does not take into account social and other factors and therefore cannot make testable predictions.

Green and Kreuter (1999) believe that the Theory of Reasoned Action (TRA) addressed some of the limitations of the HBM. This theory focuses on theoretical constructs concerned with individual motivational factors as determinants of the likelihood of performing a specific behaviour.

#### **2.4.6 THE THEORY OF REASONED ACTION AND PLANNED BEHAVIOUR**

The Theory of Reasoned Action (TRA) was first introduced in 1967 and is concerned with the relationship between beliefs, attitudes, intentions and behaviour (Glanz et al, 1997). Ajzen and Fishbein (1980) developed the TRA in an attempt to understand the relationship between attitudes and behaviour. They found that attitude towards a behaviour is a much better predictor of that behaviour than attitude toward the target at which the behaviour is directed. This is explained as follows:

The TRA suggests that ‘a person’s intention to perform a behaviour is the most important determinant of actual behaviour and that this is determined by their attitude towards the behaviour as well as the subjective norms (societal expectations) associated with the behaviour’. The notion of perceived behavioural control also informing behavioural intention is added by the theory of planned action. Perceived behavioural control refers to the subjective belief that one can perform a behaviour (Petersen et al 2010, p. 22).

Ajzen and Fishbein (1980) believe behavioural intentions are derived from two parallel cognitive processes. The first involves consideration of the individual’s own attitudes towards the behaviour and the second involves consideration of the relevant social norms. Attitudes are concerned with beliefs about the behaviour under consideration and comprise two elements: an appraisal of the likelihood that significant others would wish the individual to engage (or not) in the behaviour under consideration, and their motivation to comply with these expectations (Ajzen and Fishbein, 1980). [Significant others refer to friends, family members or other people whose opinions are important to the individual.]

As established, TRA focuses on theoretical constructs and the relationship between attitudes, beliefs, intentions and behaviour. Attitudes towards behaviours are believed to have their source in an individual’s beliefs and in a value judgement of behaviour. These may be closely tied to perceived societal norms, values and expectations or pressures – termed subjective norms (Glanz et al, 1997).

Constructs of mediating factors connect the various types of perceptions with the predicted health behaviour (Glanz et al, 1997; Petersen et al 2010):

- Demographic variables (such as age, gender, ethnicity, occupation)
- Socio-psychological variables (such as social economic status, personality, coping strategies)



- Perceived efficacy (an individual's self-assessment of ability to successfully adopt the desired behaviour)
- Cues to action (external influences promoting the desired behaviour, may include information provided or sought, reminders by powerful others, persuasive communications, and personal experiences)
- Health motivation (whether an individual is driven to stick to a given health goal)
- Perceived control (a measure of level of self-efficacy)
- Perceived threat (whether the danger imposed by not undertaking a certain health action recommended is great)

An assumption of the TRA is that the individual has the resources, skills, or opportunities to engage in the desired action. Given that this is generally not the case, Ajzen and Fishbein (1980) added a further dimension: that of control over the intended behaviour (Green and Kreuter, 1999). This reflects the perceived ability of the individual to engage in the desired behaviour. Facilitating or inhibiting factors include both internal control factors (skills and information for example) and external control factors (opportunity and dependence on others for example). Perceived control combines attitudes and perceived norms to form an intention to engage in a particular behaviour. This larger model is termed the Theory of Planned Behaviour (TPB).

TRA emphasizes the multiple influences of an individual's own attitudes, perceptions of the attitudes of significant others, and perceived behavioural control, on the intention to perform health behaviours. TRA assumes a causal chain where beliefs are linked to intentions and attitudes and an evaluation of outcomes measured on a bipolar 'good' – 'bad' scale (Glanz, 1997).

*Using Stimulant Medication for Children with ADHD: What Do Parents Say?* explores decision making processes of parents whose children have been diagnosed with ADHD (Charach, Skyba, Cook and Antle, 2006). The shared experiences of parents regarding assessment, diagnosis and treatment are explored. In considering the approaches outlined above, the authors reflect parents as experiencing: 1) a feeling of confusion, blame and responsibility for their child's behaviour, 2) a need for time to digest and reflect upon information about their child's difficulties and to consider treatment options, and 3) a strong desire to do what is best for the child, balancing treatment benefits against concerns about safety, stigmatization and respect for the child's wishes.

In deciding to try medication, parents had fears about the safety of medication, faced a lack of understanding from family, friends and other influential people and endured the negative portrayal of medication in the media. A theoretical can assist us in making sense of this decision making process.

## **2.5 IN SUMMARY**

In explaining and understanding a patient's frame of reference regarding health care decisions, the socio-psychological theories, the Health Belief Model and the Theory of Reasoned Action and Planned Behaviour, provide a useful framework for understanding the decision making process parents negotiate in seeking treatment for their ADHD child. The Health Belief Model offers us theoretical insight into the appraisal process in evaluating treatment options and the Theory of Reasoned Action and Planned Behaviour encourage awareness of intentions, beliefs and attitudes as significant determinants in the decision making process. Used in combination, these two models will inform an understanding of the factors influencing a parents' decision to use psycho-stimulant medication and factors that motivate to medication as a preferred treatment option for their ADHD child.

## **CHAPTER THREE:**

### **RESEARCH METHODOLOGY**

This chapter provides an overview of the methodology employed in this research. The specifics of the research design, sampling and the collection and analysis of data will be discussed as well as justification for use of these. As it is relevant to this research, some brief comments on reliability and validity are included as well as acknowledgement of several limitations related to the selected methodological approach. This chapter concludes with reflection on significant ethical considerations.

#### **3.1 THEORETICAL FRAMEWORK**

Qualitative research is a form of social inquiry that focuses on the way in which people interpret and make sense of their experiences and the world in which they live. Guided by the aim of endeavoring to explore the behaviour, perspectives, feelings and experiences of people, qualitative researchers seek to understand the social reality of individuals, groups and / or cultures in an attempt to investigate the meaning of social phenomena as experienced by the people themselves (Daymon and Holloway, 2002; Malterud, 2001).

Lofland (1971, p.36) describes the qualitative study of people as a ‘process of discovery...[as a process of] learning what is happening’. In addition to describing the experiences of others in depth, qualitative measures seek to explore people’s lives, their subjective experiences and what interactions means to them, in their own words, within their specific contexts.

It is the intention of this study to explore and seek to understand the factors that shape a parents’ decision to use psycho-stimulant medication in treating ADHD in their child. In order to effectively uncover and examine these factors within a context of acknowledging subjective, individual experiences, a qualitative methodological approach is employed. In attempting to arrive at understandings and interpretations of how people experience their social realities, this research takes a critical, interpretive approach, informed more specifically by an interpretive paradigm.

Terre Blanche, Durrheim and Painter (2006, p.6) define paradigms as ‘all-encompassing systems of interrelated practice and thinking that define for researchers the nature of their enquiry along [the] dimensions of ontology, epistemology and methodology’.

Interpretive research is a form of qualitative research informed by a framework of thinking which underlies how knowledge is created as well as the relationship between the researcher, the phenomenon under investigation and contextual influences (Terre Blanche et al, 2006). Interpretive research therefore attempts to arrive at understandings and interpretations of how people experience their social realities, defined in relation to a theory of knowledge (epistemology).

Interpretation, as the core of qualitative research, focuses on the meaning of human experience, on understanding this experience rather than explaining and predicting behaviour. As Terre Blanche et al (2006, p.273) write, 'interpretive [research] involves taking people's subjective experiences seriously'...seeking to understand what is real for them, by making sense of their experiences through interacting with them and in listening carefully to what they have to say.

Interpretive researchers believe reality consists of one's subjective experiences of the external world, that reality is constructed by each individual based on their own subjective life experiences. There is therefore no particular method to knowledge, or single, correct route. Reality is not a singular truth but rather an array of truths. The primary assumption of interpretive research is that knowledge, meaning and ultimately realities are acts of interpretation created through social constructs, consciousness, language and shared discourses (Creswell, 1998; Crotty, 2005). As Blaikie (1993) explains, the human experience is a process of interpretations. Reality is regarded as a complexity of socially constructed meanings, as the product of processes in which the meanings of actions and situations are negotiated through interaction (Blaikie, 1993).

With a multiplicity of experiences and realities and the different perspectives of various roles played by individuals, there is no objective knowledge which is independent of thinking humans (Creswell, 1998; Crotty, 2005). Central to an interpretive researcher is this phenomenological base, which 'stipulates that person and world are inextricably related through [a] lived experience of [that] world' (Sandberg, 2005; 43). Within this, 'the human world is never a world in itself; it is always an experienced world, that is, a world that is always related to a conscious subject' (Sandberg, 2005; 43). The existence of an objective, known, single reality, beyond subjective experience is therefore rejected as knowledge is believed to be constituted through a lived experience of reality, created through social constructions and shared discourses. At the heart of this, is a commitment to understanding subjective, lived experiences, acknowledging the significance of context.

Having a strong influence in qualitative methodologies and central to an interpretive researcher is the idea that ‘meaning can only be ascertained’ in relation to both the personal and societal contexts in which it occurs (Terre Blanche et al, 2006, p. 275). Mishler (1986) in Terre Blanche et al. (2006, p. 276) claims ‘meaning is always contextually grounded – inherently and irremediably’. In exploring and seeking to understand the decisions of parents, subjective, individual experiences cannot be divorced from the contexts within which they occur.

In addition to the above, an interpretive approach acknowledges the researcher as the primary instrument in both the collection and analysis of data (Terre Blanche et al, 2006). My presence in this research cannot be ignored. My position in choices made regarding sampling, collecting data, its analysis, interpretations, the assimilation of findings and conclusions are influenced by my own location within a social world and in relation to the participants engaged. My own presence requires appropriate description and interpretation (Terre Blanche et al, 2006). Recognition of the self as an instrument in research necessitates acknowledging being a co-constructor of knowledge.

Informed by an interpretive paradigm, this research is undertaken as a journey of understanding, in context, portraying subjective experiences while recognizing the significance of my own influence.

### **3.2 RESEARCH DESIGN**

In order to facilitate a rich store of subjective information a semi-structured interview was the design of choice for this research. According to Terre Blanche et al. (2006, p. 297), ‘conducting an interview is a more natural form of interacting with people than making them fill out a questionnaire, do a test, or perform [an] experimental task’. Interaction in interviewing provides the researcher with the opportunity to get to know participants in understanding how they think and feel. Effectively combining both closed and open questions facilitates this process. Interpretive researchers employ interviewing as a facilitator of knowledge, as a means of learning about an individual’s subjective experiences. In working towards this, creating an environment of openness and trust, encouraging authentic expression is crucial (Terre Blanche et al. 2006). Within this environment, personal experiences and the contexts in which they occur may be explored and better understood enabling us to make sense of other people’s lives, to find meaning. Consistent with the interpretive paradigm, it must however be acknowledged that meaning created in interviewing is co-constructed – the product of an inter-personal exchange between researcher and participant.

In exploring decision making processes and in seeking to understand, in context, specific decisions made, an extended personal interview based on a semi-structured guide, incorporating both closed and open questions or probes was deemed the most appropriate and useful design method for this study.

The design employed aims to explore the following, more specific questions:

- What factors shape a parents' decision to use psycho-stimulant medication to treat their ADHD child?
- How was the decision making process negotiated and experienced?
- What challenges (personal and / or social) were experienced in the decision making process?

### **3.2.1 RESEARCH PARTICIPANTS AND SAMPLING**

Given the time constraints and the intended scale of this research, a sample size of ten parents was decided on. It is acknowledged that a larger sample size with more interviews would have been favourable – this will be recognized as a limitation of this study. Despite the relatively small sample size, this did not impact on the intention of this research which is to explore and seek to understand the experiences of parents in their decision making process.

Participants for this study were selected on the basis of the following criteria: Participants had to be: **a)** the primary caregiver of a child. **b)** The primary caregiver of a child clinically diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD), all subtypes included. **c)** Using psycho-stimulant medication, prescribed by a doctor or specialist, as treatment for this disorder for the child, where the child was being treated for this disorder only and had not been diagnosed with any comorbid condition.

Initially it was my intention to interview both parents. As research was undertaken, it was evident that it would not always be possible to interview both parents. In many instances, families consisted of a single parent household. This was for the reason of divorce, death or one parent working in another part of the country. When possible and applicable, both parents were interviewed together.

As it was necessary for participants to fulfill the criteria outlined above, non-probability sampling was employed. A combination of sampling techniques was used: purposive sampling, quota sampling and snowball sampling. The techniques of purposive and quota sampling were necessary to ensure firstly that the intended sample size of ten was met and secondly that all participants met the stipulated requirements. As the topic of medication is a personal one, the technique of snowball sampling was used effectively in enabling me to fulfill my criteria for participants.

The snowballing or chain referral technique resulted in participants referring others who wanted to be involved in contributing to this study. This combination of techniques satisfied my specified sample requirements. It is acknowledged that the sampling techniques employed have implications in terms of validity and reliability – this will be commented on in due course.

### **3.2.2 DATA COLLECTION METHODS AND INSTRUMENTS**

In line with the interpretive approach, semi-structured interviews were selected as the most appropriate and effective method of data collection. This type of interview incorporated both closed and open questions, encompassing a loose structure yet allowing for the natural flow of conversation. This process offered the opportunity to get to know the participants, to understand their subjective worlds, in context – in line with the aims of this study. Interviewing as a technique was deemed the most suitable method to explore how parents experience negotiating treatment options as well as the factors influencing treatment decisions.

Personal face to face interviews were conducted with all participants. Interviews were conducted at a venue of the participant's choice. This was done in order to allow each participant the freedom to choose a place in which he / she felt most comfortable. There was also the matter of being at a location most convenient for the participant. All participants opted to have interviews conducted at their own homes. Interviews were conducted in areas free from distractions and interruptions with only the researcher and the participant(s) present. The semi-structured approach encouraged a comfortable environment of openness and authenticity. Participants were relaxed and spoke freely, several commented on appreciating the opportunity to explore their journey.

To ensure an accurate account of the data collected, with the knowledge and permission of the participant(s), all interviews were recorded and transcribed by the researcher. Transcriptions were to ensure content accuracy to enable thorough content analysis. To further ensure accuracy, participants were given the opportunity to read their transcribed interviews. Once transcribed, recorded interviews were deleted from the recording device.

### **3.2.3 COMPOSING THE INTERVIEW GUIDE**

The function of the interview guide was to facilitate discussion in an open-ended manner, to enable maximum understanding around parents' decision making processes and influencing factors. On understanding decision-making behaviour regarding treatment, an assessment of the literature suggests several content areas to be relevant. These include: a) current knowledge base (in this case regarding ADHD and psycho-stimulants); b) social support (related to this is the confusion, blame and responsibility parents experience following diagnosis; c) attitudes and beliefs (perceptions of risk, of severity, of benefits and of barriers as well as of psycho-stimulants) and d) motivators to change (coupled with doing what is best for the child).

As the intention was to engage participants in free speech, the structure of the interview guide was organized around these several broad themes whilst still being mindful of encouraging participants to explore their own subjective experiences. Closed ended questions were incorporated for comparative purposes. Please refer to the appendix for a copy of the interview guide.

### **3.2.4 DATA ANALYSIS METHODS**

Interviews conducted reflect the personal experiences of parents negotiating treatment for their ADHD child. In light of this, an interpretive thematic analysis technique was employed. This is to place the real-life experiences of parents within a broader perspective from a position of empathetic understanding. Specifically though, thematic content analysis guided analyzing and interpreting data.

Thematic analysis is not tied to any particular epistemology or discipline. Many researchers use thematic analysis as a way of getting close to their data and developing a deeper appreciation of the content. In its simplest form, thematic analysis is a categorizing strategy for qualitative data, guiding researchers as they move their analysis from a broad reading of the data towards discovering patterns and developing themes. As Boyatzis (1998, p. vii) writes, thematic analysis is a process of 'encoding qualitative information' where the researcher develops 'codes', words or phrases that serve as labels for sections of data. According to Boyatzis (1998, p. vii), codes refer to 'a list of themes, a complex model with themes, indicators, and qualifications that are causally related; or something in between these two forms'.



Thematic analysis seeks to identify relevant and common meaningful themes as they emerge through engaging with and understanding the collected data. The process of coding facilitates this identification in conjunction with observations made. Emerging themes are identified through direct observation (at the manifest level) and / or as underlying phenomena (at the latent level) (Boyatzis, 1998).

Although time consuming, this approach provides meaningful structure to rich, insightful information. Thematic analysis consists of familiarization and immersion – inducing themes – coding- elaboration – interpretation and checking. As explained, it encompasses: Recognizing emerging themes and patterns, developing a coding system, the encoding of information and interpreting the themes within the context of the conceptual framework thereby consolidate new knowledge.

Discovering themes is at the heart of qualitative data analysis. This comes from reviewing rich textual content. Techniques used in the discovery of themes in texts are based on: (1) an analysis of words (word repetitions, key-indigenous terms, and key-words-in contexts); (2) a careful reading of larger blocks of texts (compare and contrast, social science queries, and searching for missing information); (3) an intentional analysis of linguistic features (metaphors, transitions, connectors); and (4) the physical manipulation of texts (unmarked texts, pawing, and cut and sort procedures). (Bulmer, 1979; Strauss, 1987; Maxwell, 1996).

A combination of multiple techniques, used in a sequential manner, was most effectively employed in the analysis of the data collected in this research project.

In the early stages of exploration, a thorough reading and pawing through of the data was engaged in. As a process, pawing begins with proofreading the material and simply highlighting phrases which make some ‘inchoate sense’ (Sandelowski, 1995: p. 373). In handling data multiple times, a feel for the material is gained. Bernard (2000) refers to this as the ocular scan method, otherwise known as eyeballing. Initial undeveloped, formless data begins to become more meaningful. By living with the data, being immersed in it, patterns and themes emerge (Bogdan and Biklen, 1982).

The specific process followed included the following:

Using multiple copies of transcribed interviews (including post-interview notes) the researcher marked with a highlighter all details relevant to the topic, guided by the specific research questions. From the highlighted areas, distinct units of meaning were marked. These meaning units were separated by a break or change in meaning, being careful to retain all information relevant to understanding a meaning unit within the meaning unit – this was done to guard against relevant information becoming disconnected from its source.

Similar units were grouped together and coded, for example: 1-16 for interview # 1, page 16. Each grouping of units was labeled as an initial category (theme) using key words or phrases copied from highlighted texts. These were revised as data was sorted and coded. All interview transcripts endured a process of the identification of distinct units, the grouping and regrouping similar and dissimilar units, and then labeling and re-labeling. Categories were collapsed and / or subdivided as appropriate. Comparisons were made between paragraphs and across informants. This assisted in the identification of categories. An analysis of word repetitions was also useful in this stage of the analysis. This approach of cutting and sorting considered all text passages in relation to a major category and related sub-category. The identification of any metaphors or similes also endured a process of marking, cutting and sorting.

After a few days, the original interview transcripts were re-read, initially without looking at the identified units or categories. Meaning units and categories were then returned to and reconsidered. Units were redistributed and re-labeled as appropriate. Categories were then looked over as a whole and considered in relation to the topic. These finalized categories emerged as formal themes.

### **3.3 ETHICAL CONSIDERATIONS**

Bogdan and Biklen in Blaxter, Hughes and Tight (1998) propose four core ethical principles guiding research. These include: protecting identities at all times so as not to harm participants in any way; always treating participants with respect throughout the research process; telling the truth when writing up information and negotiating the terms of the research in a contract. In addition to these, informed consent and correctness of presentation were important ethical considerations.

As a principle of self-determination, informed consent encompasses the aspects of individuals having sufficient information for making a decision; that the decision is voluntary and that the individual is capable of making the decision (Punch, 1994).

In satisfying informed consent, all prospective participants were fully informed through a process of oral dissemination of information as to the nature of the research. In conjunction with this, all were handed an official letter on a university letter head from the researcher and the research supervisor stating the project title and an explanation of its aims and objectives in terms understandable by the lay person. A copy of this is included in the appendix. This letter provided the names, affiliations and contact details of the researcher, the supervisor and an administrative staff member should additional information be required. In addition to this, it was thoroughly explained to prospective participants how the research topic was identified, the criteria a prospective participant was required to meet, how research would be conducted, followed by specific details regarding what would be expected of those who agree to participate, the time it will involve, any risks and that there will be no benefits from participation. Details regarding how data would be analyzed were also provided. Prospective participants were advised that interviews were to be recorded and transcribed by the researcher.

Confidentiality was assured – no names or identifying details were to be incorporated in the study, participants are simply referred to a respondent 1, 2, 3 and so on. It was also explained that the decision to participate is entirely voluntary and that non-participation will not result in any disadvantage or consequence of any sort. Prospective participants were also made aware that they are able to withdraw at any stage, for any reason and without recourse. Potential participants were given a week to read this letter and to consult with friends / family / the university to ensure their decision to participate thoroughly meets all aspects of informed consent.

From those who were approached as prospective participants, parents who were happy to participate were then asked to sign and return a declaration stating that they understood the contents of the letter and the nature of the research project and consented to participate on the understanding that they may still withdraw at any stage as previously mentioned.

The raw data generated from the interviews conducted in the form of recordings was typed up verbatim as transcriptions. As correctness of publication of data is part of the researcher's accountability and influences the value of the study, participants were given the opportunity to read their transcribed interviews. Voice recordings were then deleted.

Ensuring the identity of all participants remains anonymous is a way of honouring the participants trust and the professional relationship (Punch, 1994). Whilst some specific demographic details were required in responses to closed ended questions, no identifying characteristics were used. All participant information has been kept confidential. Signed consent forms are kept in a secure place and are accessible by the researcher only. Anonymity has been ensured by referring to those who participated as respondent 1, 2...No information was required or presented that identified any participant or other parties in any way.

Once completed, participants will be offered a copy of this research dissertation.

Being thoroughly familiar with an ethical code of practice in research and in operating strictly within a defined ethical framework, ethical considerations have been addressed.

### **3.4 VALIDITY AND RELIABILITY**

The questions of validity and reliability within qualitative research methods are just as important as within quantitative methods although they may have to be treated somewhat differently. For Golafshani (2003) our understanding of the traditional meaning of reliability and validity has changed. When considered from a qualitative researcher's perspective, reliability and validity are conceptualized as trustworthiness, rigor and quality in a qualitative paradigm. For Whitemore, Chase and Mandle (2001) qualitative research validity and reliability are an integrated system where primary and secondary validity and reliability research criteria are identified. Primary validity and reliability criteria include credibility, authenticity, criticality and integrity. Secondary validity and reliability criteria include explicitness, vividness, creativity, thoroughness, congruence and sensitivity. According to Whitemore et al, (2001) for research to be valid and reliable, it is necessary to meet all of the primary criteria. Meeting the secondary criteria is guided by the epistemological stance of the researcher.

Considering the primary criteria, the following was explored:

In terms of credibility – do the results of the research reflect the experiences of participants in a plausible way (Whitemore et al, 2001)? A conscious and consistent effort was made to fully immerse in the selected methods of both data collection and analysis. Selected methods were also to facilitate interpretation of meaning. In addition to this, semi-structured interviews encouraged participants to speak freely.

In terms of authenticity – do descriptions of behaviour show an awareness of subtle differences in the voices of all participants (Whitemore et al, 2001)? The thematic content analysis technique allowed for the emergence of different experiences across all participants to be considered. In addition to this, care was taken not to separate material quoted from its source.

In terms of criticality – is the research critically evaluated? (Whitemore et al, 2001)? Throughout the research process, the researcher remained aware of a position as a co-constructor of knowledge and meaning. In addition to this, input from the research supervisor was considered invaluable.

In terms of integrity – does the researcher show repetitive checks of validity (Whitemore et al, 2001)? This was ensured in the ethical considerations, providing participants with the opportunity to read their transcribed interviews, taking time to consider and re-consider emerging themes and acknowledging research bias.

Relevant to this research, the following secondary criteria were considered:

Sensitivity – has research been conducted in a manner that is sensitive to both individual and societal contexts (Whitemore et al, 2001)? Research was conducted from a position of empathetic understanding. Interviews were held at a location most comfortable and convenient for participants. Giving participants the opportunity to review transcribed interviews allowed scrutiny for correctness of representation. All other ethical considerations relevant supported sensitivity.

Vividness – have descriptions been portrayed with clarity (Whitemore et al, 2001)? Care has been taken to provide a clear overall picture of each participant so that experiences may be explored in context. It was considered of primary importance that those reading this research were able to gain a sense of familiarity with each participant.

One final comment on validity and reliability is on the issues of generality and opportunity to replicate. There are instances where findings from qualitative data can be extended to people with characteristics similar to those in the study population and where replication may be possible. With this research, however, generalizability and replication are neither an intention nor an objective. The focus remains exploring and understanding the experiences, opinions, beliefs and challenges of the selected participants regarding factors mediating decision making in the specific instance highlighted.

Located within a qualitative, interpretive framework, the intention is to investigate the narratives and experiences of the participants. In light of this, issues of validity and reliability will be reflected as a limitation of the study but are not considered to detract from findings in any way.

### **3.5 LIMITATIONS OF THE METHODOLOGY**

Limitations of the methodology can be identified in a lack of generalizability and little opportunity to replicate. As has been previously indicated, generalizability, replication and consistency of results have never been an intention of this research.

Exclusive use of interviews as a data collection method may also be identified as a limitation. Interviews constitute situations in their own right – participant responses may be reflective of that particular situation. The semi-structured interview and combination of both open and closed ended questions did however provide excellent opportunity to probe and thereby thoroughly explore issues. The concern that responses were not relevant or appropriate is unfounded.

The sample size may be viewed as a limitation. As discussed earlier, considering time constraints and the intended scope of this research, ten parental interviews was deemed appropriate and adequate, particularly considering representation was not intended.

The sampling techniques may also be considered a limitation. In light of the specific criteria participants had to fill and bearing in mind confidentiality related to medication, the sampling techniques were appropriate and in line with both the theoretical framework and the aims of the research.

One final consideration in methodological limitations is acknowledgement of the researchers influence in the interpretation and analysis of the data, as the co-creator of meaning. This influence on the identified themes and findings reported on cannot be denied or ignored. Interpretations, the presentation of findings and results have been approached in a mindfully aware manner where the researcher has been fully cognizant of a personal presence in this research. It is within this territory that experienced supervision and self-reflection proves invaluable.

## **CHAPTER FOUR: DISCUSSION OF RESULTS**

The interviews conducted reflect the personal experiences of parents negotiating and deciding on treatment for their ADHD child. The discussion that follows specifically focuses on understanding the factors that influence the decision making process and on answering the research question: ‘what motivates to medicate?’

As discussed in the preceding chapter, an interpretive thematic analysis technique was employed to give meaning to the rich qualitative data collected.

Mauthner and Doucet (1998) explain that any interpretation can be done in a multitude of ways and that all research contains biases and values, specifically with regard to the aims of the study and the theoretical position of the researcher. The analysis and discussion that follows takes into account an acknowledgement and awareness of my own position as a co-creator of reality.

The themes chosen have been done so in response to the stated research questions and due to their presentation as recurrent and / or dominant in nature across the semi-structured interviews conducted. Despite operating within a framework of identified themes, it is necessary to emphasize a recognition of the individuality of the experiences of each participant interviewed. It is not my intention to categorize and label. Extensive quotes have been used to illustrate individual points and experiences effectively, as one of the primary goals of this research is to give a voice to the participants, who often convey messages in a more powerful manner than academic language permits.

A significant challenge has been remaining focused on the scope of this study, being cognizant of relevance of material in terms of discussions undertaken. With this in mind the analysis that follows is guided firstly by themes identified as reflecting factors influencing the decision making process followed by themes identified as reflecting motivators to medicate.

This chapter begins with the following table reflecting a tabulated overview of the sample followed by an introduction those interviewed. R1, R2 and so on will be used when quoting various respondents.

#### 4.1 TABULATED OVERVIEW OF THE SAMPLE

<b>Respondent</b>	<b>Child's Gender</b>	<b>Child's Current Age</b>	<b>Age at Diagnosis</b>	<b>Process Initiated By</b>	<b>Diagnosed by</b>	<b>Treatment Prescribed</b>	<b>Treatment Selected</b>	<b>Current Treatment</b>
1	Male	5	5	Teacher	Pediatrician	Ritalin 10mg	Ritalin 10mg	Ritalin 5mg
2	Female	7	7	Teacher	GP	Concerta 27mg	Concerta 27mg	Concerta 36mg
3	Male	10	8	Teacher	GP	Ritalin 10mg	Natural Supplements	Concerta 36mg
4	Female	10	9	Teacher	GP	Concerta 36mg	Concerta 36mg	Concerta 36mg
5	Male	6	6	Parents	Psychologist	Ritalin 5mg	Ritalin 5mg	Ritalin 5mg
6	Female	11	9	Teacher	GP	Ritalin (does not recall dose)	Ritalin (does not recall dose)	Concerta 36mg
7	Male	10	9	Teacher	GP	Ritalin 10mg	Natural Supplements	Ritalin 10mg
8	Female	8	7	Parent and teacher	Pediatrician	Concerta 18mg	Concerta 18mg	Concerta 36mg
9	Male	9	7	Teacher	GP	Concerta 18mg	Concerta 18mg	Concerta 36mg
10	Female	9	8	Teacher	GP	Concerta 18mg	Concerta 18mg	Concerta 27mg



## **4.2 THE RESPONDENTS**

### Respondent 1:

This respondent is 39 years old. She has been married for ten years. Respondent 1 and her husband have one child who is five years old. He is in Grade R at a private school in the Hillcrest area of KwaZulu Natal. Respondent 1 works as a grade 5 teacher at a government school. Throughout the interview, she presented as relaxed and spoke freely. Respondent 1's husband was unable to attend the interview - he was attending meetings in Johannesburg the week of the interview. It was respondent 1's preference to continue without him rather than re-scheduling.

### Respondent 2:

Respondent 2 is a 40 year old female. She has been married for nine years and has two girls, one age 7, the other age 4 and she is expecting her third child in December this year. Her seven year old daughter is currently in Grade two at a government school in the Kloof area of KwaZulu Natal. Respondent 2's youngest daughter attends a nursery school close to home. Respondent 2 is a stay at home mom, her husband is an accountant and he did not wish to participate in the interview. Respondent 2 presents as a lively, outgoing woman.

### Respondent 3:

Respondent 3 is a 37 year old female. She is married (second marriage) with one child (son) from her first marriage and three children from her second marriage. This respondent works half day as an administrator in Kloof. The children in the home range from age 2 to age 10 - life with four children is described as 'very chaotic'. Her oldest child is currently in Grade 3 at a government school in the Hillcrest area of KwaZulu Natal. Her second child, a girl, is in Grade 1, her third child, another girl, in pre-school and her youngest, a boy, stays at home with their domestic worker. This respondent's current husband works in Logistics. As he has a very stressful and demanding job, he was unable to commit to participating in the interview.

Respondent 4:

Both husband and wife are in their 40's. They have been married for 13 years. They have three children: one in Grade 7, another in Grade 4 and their youngest in Grade 2. Their children attend a government school in the Hillcrest area of KwaZulu Natal. Both mom and dad work – mom as a car sales person and dad as an auto electrician. Their 7 year old daughter has struggled at school for the past three years. Dad has always been very reluctant to try medication for his daughter's severe inattention.

Respondent 5:

Respondent 5 is 29 years old. She has two children, a daughter in Grade 3 and a son in Grade 1. Both children attend the same government school in Westville, KwaZulu Natal. This respondent is recently divorced although she has been separated from her husband for 18 months. Earlier this year she was called in to see her son's teacher with regard to behavioural issues.

Respondent 6:

This respondent is a 42 year old single dad who runs his own business from home.. His wife passed away a year ago. He has two children, a son in Grade 7, age 13 and a daughter in Grade 5, age 11. Both children attend the same government school in the Westville area of Kwa Zulu Natal. This respondent's daughter has been taking psycho-stimulants for the past two years.

Respondent 7:

This mother and father (ages 37 and 40 respectively) have three children ages 11, 7 and 4. Dad is a hairdresser in the Pinetown area of Kwa Zulu Natal and mom stays at home, she has a small internet business. This couple has been married for 14 years. Their 11 years old is in grade 6 at a government school in Westville, KwaZulu Natal. Their 7 year old is in grade 1 at the same school and their 4 year old goes to the local pre-school. Both parents are very busy with their work and their children.

Respondent 8:

Respondent 8 is 41, she and her husband have been married for 9 years. This respondent has recently become a stay at home mom (6 months ago). Prior to this she worked as an administrator at a law firm. She resigned to be more available for the children. Respondent 8 has two children, two girls. One age 8 and the other age 4. The family live in New Germany in KwaZulu Natal. Their 8 year old attends a government school in their area. He is in grade 2. Their 4 year old goes three mornings a week to the nursery school down the road. In the run up to starting medication, their 8 year old was a highly disruptive influence in the home. The respondent's husband preferred not to participate in the interview.

Respondent 9:

Respondent 9 is 35 years old. She has been married for 6 years. She and her husband married when their son was 3 years old. The couple has two children, a 9 year old son and a 2 year old girl. Their 2 year old stays at home with the domestic worker, their son is in grade 3 at a local government school in Pinetown, KwaZulu Natal. This respondent is a personal assistant and her husband is a warehouse manager who was attending a training workshop at the time of the interview. He was therefore unable to be present.

Respondent 10:

Respondent 10 is 35 years old. She has two children, one girl age 8 and a boy age 3. This respondent has been married for 13 years. She works from home offering book keeping services and her husband is a plumber. They live in the Hillcrest area of KwaZulu Natal. Their daughter goes to the local primary school. She is in grade 3 and their son attends a pre-primary school just down the road from their house.

### **4.3 FACTORS THAT INFLUENCE THE DECISION MAKING PROCESS**

An analysis of the transcribed interviews reveals some significant themes which provide us with insight into factors that influence the decision making process. Discussion of each of these relevant themes follows:

#### **4.3.1 KNOWLEDGE OF THE DISORDER**

In assessing the information respondents have regarding ADHD, this is best presented as being separated into (a) a general understanding of the disorder, (b) etiology, (c) diagnosis and (d) treatment.

##### **(a) A general understanding of the disorder**

Respondents explain ADHD in one or more of the following three ways:

- Most commonly (6 out of the 10 respondents), ADHD is explained in terms of the symptoms exhibited and the behaviours displayed by their children. Respondents were confident in listing the behaviours that they associated with an ADHD child: poor concentration, hyperactivity, being impulsive, not being able to focus, forgetful, disorganised.
- 5 out of the 10 respondents explain ADHD as a behavioural problem or issue.
- 4 out of the 10 respondents identify ADHD as being located within the brain and related to inefficient brain functioning – this is relayed in simplistic terminology and without any detailed understanding:

‘I understand ADHD to be a neurological thing where the wiring of the brain does not work as it should. The brain then kind of gets its wires crossed and behaviour gets a bit out of control’ [R 5].

‘I believe it is an inefficiency in brain functioning which makes focus and concentration more difficult, you are very effected by your surrounding environment and you are easily distracted or over excited meaning both behaviour and focused attention are a problem’ [R 6].

Findings indicate that respondents have both a vague and limited understanding of ADHD in general as a disorder. Without exception, all of the ten respondents found it difficult to articulate meaning. Each respondent offered their own version of what they understood ADHD to be, they were able to list several associated behaviours but could not provided an accurate definition.

## **(b) Etiology**

In an attempt to assess the level of knowledge respondents have regarding more specific aspects of ADHD, each respondent was asked what they knew about causes of ADHD.

Nine out of the ten respondents replied not knowing anything about what causes ADHD. One of these nine respondents replied that it (ADHD) is possibly caused by a ‘change in lifestyle’ and ‘related to the food we eat’ [R 7]. There was only one respondent out of the ten interviewed that indicated having some knowledge related to etiology. This respondent offered the following:

‘There doesn’t seem to be a clear cut cause. In most of the reading I have done, it seems to be a combination of diet, genetics, environment, individual personality traits’ [R 6].

The response above contains several interesting elements: Use of the word ‘seems’ appears suggestive of having no definitive answer, a measure of uncertainty, of not being fully sure. There is evidence of further information being accessed: ‘in most of the reading...’, indicating that this respondent has embarked on a search for more knowledge. The words ‘I have done’ suggest this additional information sought has been done independently, possibly not guided by a medical practitioner and not in conjunction with a friend or partner. This respondent also recognizes inter-related contributing factors, showing an awareness of there being no single attributing cause.

From the nine respondents who were not able to answer this question, it is evident that knowledge relating to etiology is lacking. Reflecting on responses given there is a high incidence of an absence of accurate information.

## **(c) Diagnosis**

Assessing respondent information relating to diagnosing ADHD suggests respondents are not fully informed as to the process of diagnosis – knowledge in this area is limited. As illustrated in table 6 (tabulated overview of the sample) seven of the ten respondents had their children diagnosed by a GP, two of the ten had their children diagnosed by a specialist pediatrician and only one respondent had their child diagnosed by a psychologist. The respondent whose child was diagnosed by a psychologist states the process of diagnosis was explained ‘very carefully’ [R 5]. This respondent showed a clear understanding as to how ADHD should be diagnosed.

All of the respondents whose children were diagnosed by a GP relayed a similar experience where they spent an extended period of time in an appointment with their family doctor where he / she observed the child and answered many parental questions. In conjunction with teacher reports and / or feedback, diagnosis was then made.

The respondent whose children were diagnosed by a specialist pediatrician relayed a similar experience to those whose children were diagnosed by their GP:

‘...there is a kind of check list that you go through with the doctor, something like ‘does your child have or do x, y, z’. Also observation – the doctor spent about 45 minutes to an hour observing her while we were in the appointment’ [R 8].

‘He (the doctor) asked us loads of questions about all sorts of things and was continually watching our son throughout the consultation. Before coming to the appointment we had been asked to fill out this paperwork, a Connors Rating Scale. In our appointment he (the doctor) showed us one the teacher had also completed...we just kind of went along with things, doing what we were told before the appointment and then when in the appointment’ [R 1].

Findings suggest the respondents are not fully informed and do not adequately understand the process of diagnosing ADHD. In addition to this, it is evident that ADHD is diagnosed largely by the family doctor and that this diagnosis is the result of an extended consult with the parents and child where the doctor has a single interacting encounter with the child.

#### **(d) Treatment**

Assessing respondent information relating to ADHD treatment options, findings reveal respondents to be significantly familiar with the two psycho-stimulants (Ritalin and Concerta) prescribed most frequently in the pharmaceutical treatment of ADHD. All of the ten respondents stated specifically Ritalin and Concerta. Although respondents are familiar with the trade names Ritalin and Concerta, it is doubtful that their understanding goes beyond that. Specific to this sample, ADHD treatment knowledge is clearly defined by and limited to knowing the trade names Ritalin and Concerta.

It is clear from the findings that the respondents interviewed have some significant gaps in their knowledge based regarding all aspects related to ADHD. All participants reside within the Upper Highway area of KwaZulu Natal (an area extending from approximately Westville up to and including Hillcrest). This is a well-established urban residential area encompassing some affluent suburbs such as

Kloof for example. The children referred to by the parents interviewed attend either local government or private schools. In addition to this, the medical intervention received was via private health care practitioners: the family GP, a specialist pediatrician or a psychologist. It is interesting that despite having access to premium health care facilities; a significant gap in acquiring accurate information exists.

As a significantly researched and publically discussed disorder (to the point where parents are noticeably familiar with, and able to correctly name, the leading drug treatments), how do we explain such an absence of accurate information and what are the implications of this as an influencing factor in treatment decision making?

Jackson and Peters (2008, p.2731) believe ‘it is important that parents are able to access accurate information’ relating to an understanding of specifically what ADHD is, etiology, diagnosis and treatment options. Brinkman and Epstein (2011, p.52) maintain that decisions related to treatment preferences are significantly influenced ‘by information (and / or misinformation) received from a variety of sources, including social networks, the media, and health care providers’.

#### **4.3.2 INFORMATION SOURCES**

In examining factors that influence the decision making process, a significant theme emerging is the information sources respondents turn to when faced with having to make a treatment decision.

When asked about being given any reading material to review from the diagnosing medical practitioner, nine of the ten respondents replied with a single no. One respondent [R 2], whose child was diagnosed by the family GP, responded with: ‘We were referred to some websites’.

In asking those interviewed what sources of information they sought, a selection of the following was stated: the internet, google, input from friends who have experienced the same, input from their partner and input from the pharmacist when collecting their script. In terms of accessing information, it is clear that respondents were left to their own devices and accessed information from sources that were often neither accurate nor reliable.

‘I googled Ritalin...that was pretty scary. I spoke to the pharmacist when collecting the first script and he explained about the medication being quickly metabolized. He was pretty helpful and very knowledgeable’ [R 6].

Within this study, it is clear that acquiring accurate and reliable information is problematic. Within this domain, a pertinent question is raised: Is information the responsibility of the parent or patient to access, or is it the responsibility of the health care practitioner to provide? Given the availability of unregulated information on the World Wide Web, to some degree professionals have to take responsibility in advocating evidence based information which they have access to from drug representatives for example, towards psycho-education.

In considering factors that influence the decision making process, the information we have and where it comes from is a significant factor in this process as it raises an important question for the participants in this study: Would your experiences of negotiating treatment, your discussions with others and ultimately your chosen treatment have been the same if you had had accurate information, from reliable sources, relating to all aspects of ADHD?

#### **4.3.3 THE ROLE OF THE TEACHER**

Findings indicate the child's teacher plays a significant role in two distinct areas. These are firstly in initiating an intervention in being the first to create awareness as to problem behaviour and secondly in giving on going feedback which acts as a determinant as to whether or not the chosen treatment is having the desired effect.

##### **(a) The role of the teacher in initiating intervention**

In nine out of the ten interviews, initial concerns regarding problematic functioning originated from the child's teacher. It was the teacher's experience of the child within their school environment that prompted feedback to parents and initiated an intervention. Whether the intervention initiated was a change in diet, a change in routine, a change in behaviour modification approaches or referral to a Health Care Practitioner (psychologist, doctor or pediatrician), this was done in response to the teacher's observations of and interactions with the child.

'First it was the teacher...the teacher suggested we see our GP for a full medical. She also wrote a letter with her concerns and describing his behaviour in class' [R 9].

'The teacher said our daughter wasn't coping with her attention and that she was slow to finish things...she still had the same concerns after [a] month so she asked us to talk to our GP' [R 10].



‘It was into the second term of grade 1. The teacher called us in and said our daughter was really slow finishing work that she was very easily distracted and always lost stuff’ [R 2].

Findings indicate teachers play both a significant and dominant role in identifying problems with children. In nine out of the ten interviews, it was the teacher who assumed the role of creating awareness regarding the child’s functioning, stating specific concerns and equating these to the extent to which the child is coping and will cope in the time to come. In addition to this, findings suggest teachers’ play an active role in referring parents to what they believe is the appropriate next step. The role of the teacher in identifying problem behaviour and thus initiating intervention is a significant factor influencing the decision making process. Despite the significant input of teachers in this process, it is necessary to be mindful of the fact that diagnostic requirements clearly state that the symptoms have to be present in at least two environments. Considering this, it is important for the Health Care Practitioner to conduct an assessment in keeping with this requirement to ensure diagnostic accuracy.

#### **(b) The role of the teacher in assessing intervention effectiveness**

Findings suggest that whilst the teacher plays a significant role in initiating the process of intervention, the teacher also plays a significant role in assessing the effectiveness of the intervention chosen. Teacher feedback appears to have a strong influence on the decision making process parents undergo when considering an intervention.

‘The teacher called me in for another meeting. She showed me my son’s work and gave me lots of examples of things he just wasn’t finishing and listed books that went missing. She felt really strongly that whatever I was giving him was simply not working. She asked me please to call the doctor or go back and see him’ [R 3].

‘...the teacher called us in to talk about him not really keeping up in class and taking long to finish things. It was mostly him being distracted and very disorganized. ..the teacher called us in again about a month later with all the same issues. She asked us please to see our doctor. She felt really strongly that as a result of the distraction and disorganization, he was just not coping’ [R 3].

Ongoing feedback from teachers is an important element in assessing the effectiveness of the treatment selected. It was clearly evident in pawing through the raw data that parents were called back repeatedly for parent / teacher meetings where a comparative review of the child’s behaviour was the topic of discussion. Teachers were also active in reporting back to parents when there had been dramatic improvements in the child’s functioning at school. In these instances, teacher’s endorsed and supported the intervention chosen.

This ongoing feedback plays a substantial role in influencing decisions made, particularly when teachers are able to provide comparative information and real evidence in terms of the child's work output.

#### **4.3.4 ACCEPTANCE / UNACCEPTANCE OF DIAGNOSIS**

As there is no definitive test for ADHD, its diagnosis relies on assessing a check list of behaviours and considering the degree to which significant impairment in functioning is experienced. This relies on an interpretation of the child's behaviour in their home and school environments – several parents in this study feel this comes down to a matter of opinion. As stated in 4.1.3 above, in nine of out the ten interviews, parents revealed it was the teacher who first reported some elements of problem behaviour. For these nine parents, prior to this, their child's behaviour was not considered problematic. This is a very important statement as it has implications in terms of how the condition was assessed and diagnosed and how parents subscribe to their diagnostic understanding of the condition and their subjective interpretations of where their child falls within the continuum of wellness and illness.

All parents interviewed expressed it being emotionally difficult to accept that their child needed some form of assistance / intervention. Two parents in particular [R 1 and R 4] did not agree with teacher reports and the doctor's feedback. These parents disputed ADHD in their child and for them the process of making a treatment decision was fraught with several common emotions: anger, disappointment, fear, uncertainty, denial and resistance. For R 1, probes reveal that the reasons behind these emotions come from the perception that firstly the parent felt excluded from the process of identification of issues to diagnosis and treatment options. A feeling of disempowerment was experienced: 'I felt like everything was out of my control'. In addition to this, the parent reveals a sense of feeling unheard or not listened to: '...it was like no one believed me'. Attached to this is also the parent's perception of their child being judged and / or labeled and a sense of defensiveness emerges. From R 4 probes reveal more the a sense of denial and resistance:

'I think there's no such thing. I mean, there was none of this when I was growing up...I bet some fancy person just dreamt that up one day and everyone has just bought into it...Every year every teacher made the same comments: day dreams, wastes time, is distracted, slow, work unfinished...we resisted year after year because we resisted year after year because we didn't see the lack of concentration etc that they saw [R 4].

For parents who were on board in terms of teacher feedback and recommendations made by the medical professional, treatment decision making was a logical, rational process. These parents, accepting of the diagnosis, took the approach of trusting in the expert opinion of the professional and proceeded immediately with the prescribed medication. For parents who struggled to accept their child being diagnosed ADHD, the decision making process was significantly conflicted.

‘Doctors seem to rely on input from the child’s teacher, from consulting with the parents and from observing the child in the consultation room...he [the doctor] asked us loads of questions about all sorts of things and was continually watching our son throughout the consultation’ ... ‘As much as I said my son doesn’t behave the way the teacher describes him at home, it was like no one believed me...I don’t think my child has ADHD and I don’t like that label because that’s really what it is, an easy way of saying a child is a little more challenging to deal with’ [R 1].

‘We were just not keen to use medication for something that we felt was based on opinion’ [R 7].

‘We went to the doctor for a reason and if that was his professional opinion, then we are happy to go with it...doctors and specialists deal with this every day and you have to trust their judgment and have faith in them that they will do what’s best [R 9].

Findings of this research suggest that the extent to which the parent either accepts or rejects the diagnosis, is a significant factor influencing their decision making process.

#### **4.3.5 PARENTAL BELIEFS, ATTITUDES AND PERCEPTIONS**

Working through the transcribed interviews, it is clear that each individual interviewed had their own unique experience. Every parent described their individual encounters with their child’s teacher, with the diagnosing medical professional and with significant others.

In addition to this, these experiences are further differentiated as a result of the personal beliefs, attitudes and perceptions parents hold. Some of these personal and unique attributes were expressed more directly than others. For some, the perception of ADHD was a label that meant there was something wrong with their child, for others the term ADHD equated to medication. Two of the parents interviewed were skeptical as to whether or not ADHD really existed, believing it to be a useful term adopted to give a name to a more challenging child.

Findings indicate that a parent's beliefs, perceptions and attitudes regarding teachers, medical professionals, ADHD as a disorder and modern society, are reflected in their decision making process. This can be illustrated in the following:

Respondent 3 does not know what causes ADHD and explains ADHD as

‘...a condition which means you lack concentration and focus, you are easily distracted, constantly lose and forget things and take a long time to complete things’.

In the case of respondent 3, it was the child's teacher who first raised concerns about behaviour and a visit to the doctor was the result of being called in for repeated parent / teacher meetings:

‘...the whole process was very much driven by the teacher. It certainly didn't come from me. I wasn't the one who kept saying there's a problem’.

In addition to this, this parent's attitude towards ADHD is that:

‘...it's not like something you do a blood test for, have concrete evidence for and then take meds for’...it isn't like we were told your son has x, like if he were to have some major illness. It was more like he was just struggling with certain things’.

Following several parent / teacher meetings and doctor consults which culminated in Ritalin being prescribed, the parent chose natural supplements (as a source of second opinion) as their initial preferred treatment approach. When this treatment approach did not yield satisfactory results (as per constant teacher feedback), the decision was taken to medicate. The child has now been on medication daily for 2 years (first 10mg Ritalin and now 36mg Concerta). Despite receiving very positive feedback from the teacher, no longer getting called in for parent / teacher meetings and no longer being told the child isn't coping, this parent's attitude towards medication is reflected in the following:

‘Every month I hate buying it. Every month I ask myself if it is really necessary. I don't think I will ever go and buy it willingly’.

It is clear from the detail above that the beliefs, attitudes and perceptions of this parent are significant factors influencing the treatment decision making process.

It is however necessary to be cognizant of the fact that these factors may be influential on both a conscious and / or subconscious level – individuals are often not aware of their personal underlying beliefs, attitudes or perceptions that influences thought processes and actions taken and the extent to which these inform a treatment decision.

It is also necessary to consider how beliefs, attitudes and perceptions shape, and are shaped by, our state of knowledge. This parent had no information regarding causes of ADHD yet expresses some definite opinions on a variety of topics. This parent was not given any reading material by the doctor and used casual conversations with others to extend knowledge. In addition to this, parents also have opinions as to the effectiveness of alternative treatments, eight out of the ten participants had very skeptical views on natural supplements – a general attitude towards over the counter supplements was that they were ‘a waste of time’. What informs the beliefs, attitudes and perceptions we hold? Answering this question is beyond the scope of this study but if we consider the case of respondent 3 detailed above, a pertinent question is raised: if this respondent had accurate, reliable information relating to what ADHD is, etiology, diagnosis, treatment alternatives and the specifics as to how they work, what effect would this have on the beliefs, attitudes and perceptions of the individual whose responsibility it is to make a treatment decision?

It is important that health professionals have a greater awareness of the personal experiences and concerns of treatment decision makers as misinformed individual may then hold distorted beliefs, misguided perceptions and disproportionate attitudes influencing their decision making process.

In seeking to understand the factors that influence the decision making processes of parents, findings suggest that there is no one, single factor that influences this process. However, some of the factors which are significant influencers include: the knowledge one has of the disorder in terms of a general understanding of the disorder, etiology, diagnosis and treatment; information sources accessed; the role the teacher plays both in initiating intervention and in assessing effectiveness of the selected treatment; the degree to which parents are accepting of the diagnosis and the personal beliefs, attitudes and perceptions of the decision maker.

The focus of discussion now specifically moves onto factors that motivate to medicate.

#### **4.4 MOTIVATORS TO MEDICATE**

An analysis of the transcribed interviews reveals some significant themes which provide us with insight into the factors that motivate a parent to choose medication in treating their child diagnosed with ADHD. Discussion of each of these relevant themes follows:

##### **4.4.1 ALTERNATIVES TO STIMULANTS**

A significant factor acting as a motivator to medicate relates to alternatives to stimulant medication. Findings suggest this incorporates the following issues: a) the lack of awareness parents have of alternatives to attempt before opting for stimulant medication b) the extent to which alternatives are promoted by medical professionals and c) the effectiveness of the supplements parents select.

##### **a) The lack of awareness parents have of alternatives to stimulants**

As has been established in preceding discussions, the information parents have on treatments options, other than stimulants in the form of Ritalin and Concerta, is limited. Findings indicate that parents associate ADHD treatment with medication. Parents are aware of one or two over the counter natural products, those that are more widely marketed than others but do not regard these as viable treatments - these better known alternative products are discussed in social circles between parents and are largely discounted in terms of them being effective treatments. In addition to natural supplements, other alternative interventions that parents are not aware of are dietary changes, environmental changes (classroom setting, implementing an organizational, routined structure) and behaviour modification techniques. Findings suggest that parents have a significant lack of awareness and minimal information regarding interventions that do not include medication.

‘Nine out of ten times, it’s Ritalin although I do see loads of products on the shelves in Diskem these days claiming to treat ADHD. Apparently Biostrath is meant to help with concentration but I don’t know anyone who says those natural products actually work’ [R 1].

##### **b) The extent to which alternatives are promoted by medical professionals**

Alternative treatment options in the form of natural supplements are readily available in pharmacies and health stores, some more widely publicized than others. As established, parents have limited awareness of these products. Findings indicate that when parents enquire about alternatives to medication, this is met with skepticism by the medical professional consulted and these products are not encouraged as a viable treatment or intervention.

‘Only after I said I was not keen to go the route of medication and asked what alternatives there were, did the doctor tell me about the supplements available. He was not really in favour of them though. He went on to say that there was no evidence that they worked...’ [R 3].

‘I asked if Ritalin was really necessary. The doctor replied that some alternative products have had some success but that ultimately people eventually come back to Ritalin after trying various other things’ [R 6].

‘When we said we were not keen on the medication, the doctor told us more about the natural products but was quick to say there is nothing substantial to say they were effective. He did mention diet being important’ [R 7].

It is clear from the finding that common in every interview that stimulant medication was recommended as first line treatment. It was not the case that parents were first given alternatives to attempt before going the route of medication. Stimulant medication appears to be promoted by medical professional as the preferred method of treatment based on its immediate and effective results. Even in instances where there was no clear diagnosis and there was no definitive finding that the child was indeed considered ADHD as the extent to which impairment of functioning was debatable, stimulant medication was prescribed. These finding suggest that medical professionals do not regard alternatives to medication as a viable treatment intervention for ADHD.

### **c) The effectiveness of the supplements parents select**

In addition to the lack of awareness parents have regarding alternatives to stimulants and that these alternative treatments are not promoted and encouraged by medical professionals, findings suggest that where an alternative to medication was selected, results of the chosen intervention were inconsistent and ultimately unsatisfactory. Out of the ten parents interviewed, two chose to implement supplements rather than the prescribed stimulant.

‘I was not going to just go out and get the Ritalin, I wanted to explore the alternative options first, I mean, wouldn’t you rather have your child on something natural than on prescription meds?...’ I decided on two products...some brain food thing and biostrath. For the first couple of weeks things seemed better...but it didn’t last. It was so up and down. One good day, one bad day then more bad days than good days. It must have been a good six months of trying different natural products. Of course they all made great promises and with each one I was sure it would work...the teacher called me in for another meeting...she felt really strongly that whatever I was giving him was simply not working’ [R 3].

‘We insisted trying everything other than medication first. We didn’t want medication to be anything other than a very last option...we tried two natural products in their maximum dose for around 6 weeks. We also cut out all junk food and stopped eating store bought cakes and biscuits, cokes, chips etc. Initially things changed for the positive but it wasn’t consistent. Feedback from the teacher was still that he was struggling and that his behaviour was difficult, worse’ [R 7].

For these parents, feedback from teachers was that the selected intervention was ‘not working’. Results appeared to be both inconsistent and unsatisfactory. In both cases, after having pursued the alternative route, one for a six week period, the other for a six month period, a decision was made to implement stimulant treatment. In both these cases, the motivator to medicate was the poor results of the alternative selected. In both cases the alternative was considered to have failed to produce the required outcome and parents returned to their family doctor to commence stimulant treatment which then did produce the required results.

What is also significant here is that the parents who selected natural supplements were left to their own devices when it came to product selection. Products were selected by reading what was written about the product on its box in conjunction with conversations with store assistants. In these instances, parents relied on marketing information and by stander input in selecting what they thought would be a worthwhile product.

#### **4.4.2 CONFIDENCE IN AN EXPERT OPINION**

In seeking to understand what motivates parents to medicate their ADHD child, findings suggest parents place a significant amount of value in the expert opinion of the medical practitioner consulted:

‘I really just followed what our doctor had said. I trust him and his judgment. I was happy to go with what he prescribed’ [R 6].

‘He (the doctor) pointed us in the direction of Concerta and we trusted him...we relied on the doctor’s opinion and his recommendations’ [R 8].

‘We went to the doctor for a reason and if that was his advice, then we were happy to go with it...we were happy to go with his expert knowledge...doctors and specialists deal with this every day and you have to trust their judgment and have faith in them that they will do what’s best’ [R 9].

‘We were fine to do what the doctor suggested. If that was his professional judgment then that’s what we do’ [R 10].



As is illustrated in Table 6, (tabulated overview of the sample, p. 51), eight of out the ten parents whose doctor prescribed stimulant treatment, followed through with the recommended treatment. Of these eight, three began with prescription medication the very next day, going from their appointment straight to the pharmacy to fill their script. The remaining five parents began medication within the week following their consultation.

Findings indicate a sense of confidence in the expert opinion of the prescribing practitioner and a willingness of parents to move forward with the treatment recommended. This appears to be a significant factor for parents as a motivator to medicate. There is over whelming evidence to suggest that, to a large extent, unquestioned value is placed in the opinion of the medical professional who is considered ‘the expert’ and that as the expert, they know best. To explore the nature of the doctor / patient relationship which precedes this finding is beyond the scope of this study but I would encourage further research that explored the power dynamic between doctor and patient which places the doctor in a position of such esteem and unquestioned authority.

#### **4.4.3 PRESSURE TO MEDICATE**

In seeking to understand the factors that motivate medicating an ADHD child, findings from the interviews conducted suggest parents are faced with an element of pressure to initiate this treatment intervention. The pressure to medicate appears to come in a variety of forms and from a variety of sources. In some instances this is direct pressure from teachers. For others, it was from medical professionals in their position as an authority figure and as stimulants being backed by empirical evidence as first line treatment. There were instances where pressure came from a combination of both the medical professional and the teacher. In other instances the pressure to initiate stimulant treatment was the result of social pressure where as a social construct, ADHD means Ritalin or Concerta and that to medicate is part of a now accepted social norm. Common across the different sources of pressure to medicate is the underlying persuasion encouraging parents to ‘just try it’; based on the retort ‘what do you have to lose?’ In addition to this, the failure of over the counter treatments to shift symptoms also provides parents with a reason to ‘give in’ to stimulant medication.

### **a) From teachers and medical professionals**

For parents explaining pressure to medicate from teachers and medical professionals, these parents indicate a sense of disempowerment where they feel ‘bullied’, coerced into initiating stimulant treatment. In these instances, parents feel prescribed to and a sense of loss of control and exclusion in the decision making process prevails.

‘If you are asking me how I came to the decision to use Ritalin, my response to that is that there wasn’t really a decision to make. I mean, it wasn’t like we had a choice...the teacher is telling me how badly behaved my child is and how others in class are not wanting to play with him, the specialist is sitting behind his desk telling me what my son needs and basically writing out a script so where’s my decision in that? It wasn’t this big decision we pondered over for ages. It was like a foregone conclusion – you take your child to the doctor, they make a diagnosis, they write you a script and off you go. ...I felt quite overwhelmed and pressurized by both the teacher and the doctor. I just didn’t feel like I was making a decision...When I look back, I feel a bit like I was bullied. I felt a loss of control in the situation’ [R 1].

‘...it definitely comes from the teacher. It feels like there’s a lot of coercion from them...it’s like they know best’ [R 4].

This is a significant finding as it appears that when parents are faced with the important and emotional decision regarding initiating stimulant treatment for their ADHD child, there is a strong element of coercion and a feeling of being excluded and disempowered in the decision making process.

### **b) As an accepted norm**

The following extracts from selected interviews indicate the pressure parents experience as stimulant treatment has become a perceived accepted social norm:

‘...meds are part of the 21<sup>st</sup> century – pills to make us feel better, function more efficiently. Now days whatever the issue, there’s medication to fix it. I guess poor concentration and distraction is just one of those issues we now have a way to fix’ [R 4].

‘I actually didn’t realize how common it is – so many kids these days are either on Ritalin or Concerta. That made me feel so much better’ [R 2].

‘These days it (ADHD) is really common – every other person you speak to now has a child on Ritalin [R 7].

‘...you don’t go to the doctor complaining of poor attention, lack of focus and being distracted and not walk away with a script for either Ritalin or Concerta...it was like he (son) was joining the ranks so to speak’ [R 9].

Findings suggest that to treat ADHD with medication is the accepted norm and that the stimulants Ritalin and Concerta appear common place for school going children. It is indicated that to some degree parents use this as justification to initiate medication in their own child where it is a case of everyone else is doing it anyway. It appears that in these cases, motivation to medicate is based on a sense of conformity again rather than on careful deliberation of assessing pros and cons

### **c) The underlying persuasion to ‘just try it’**

Paving through the raw material, a dominant theme emerges across several interviews in the recurring words ‘just try it’. Where parents are undecided as to initiating stimulant treatment, this particular phrase appears as consistent ‘advice’ offered by both teachers and doctors encouraging parents to take that step. In addition to this, it also appears as a deciding factor for parents in their discussions with one another:

‘He (the doctor) encouraged me to try the Ritalin on the basis of seeing what happened’ [R 3].

‘This time it was the teacher and the deputy head. Their approach that day was just to try the meds and see what happened. They asked us what we would have to lose. They said if it didn’t work, then to stop it immediately but why didn’t we just try it. They both implored us just to try it’ [R 4].

‘About a million times, between the doctor and the teacher, we were told just try it’ [Matt, interview 7].

Findings suggest that pressure to medicate comes from a variety of sources and that between other parents, medical professionals and teachers, parents are pressed to initiate treatment on a trial and error basis where they are implored by the statement ‘just try it’ followed by the argument ‘what do you have to lose’. The subconscious implication is that the advisor (motivator to medicate) has evidence based experience to monitor and control for the best treatment outcome and that there is an inherent safety in using controlled medication.

#### 4.4.4 A DEFINING MOMENT

Findings from interviews conducted indicate that a factor motivating selecting stimulant medication is a call to action where parents feel compelled to act where the decision to medicate can be triggered by a specific event or chain of events. In these instances, the decision made is not the result of careful deliberation. For one of the respondents, the trigger to act was an incident at home which could have resulted in injury to the child:

‘He would just do silly things at home but the final straw was when my ex arrived to collect the kids one morning. He had parked his car in the drive and come in...the next thing we heard was our son screaming ‘dad’. We all rushed outside and the car was rolling down the drive. He had let down the hand brake. He was so upset but just kept saying ‘I couldn’t help it, I just wanted to see what would happen’. We both knew it was time for some help’ [R 5].

Of the ten interviews conducted, this is the only instance where the intervention was initiated solely by the parents. Until this defining moment, the parents of this child had tolerated ‘silly’ behaviour which was often understood as typical boy behaviour. They had recognized their child as hard work but it was only when he endangered himself that they felt compelled to act. Motivation to medicate was triggered by this defining moment.

For the following parent, respondent 3, the defining moment was yet another parent / teacher meeting:

‘I remember the last time the teacher called me in, I just felt tired, like I was going around in circles. I constantly felt like I was taking one step forward and two steps back. It just seemed like I was getting nowhere fast. I really just wanted to put an end to it. I didn’t want to be told I needed to do something. I didn’t want to feel like it was always bad news coming from the school. I just wanted something to work’ [R 3].

In this instance, the parent experienced a sense of desperation and exhaustion in the ongoing cycle of being called to the school due to her child’s behaviour. Evidence from the teacher which provided the parent with a sense of concrete proof that the intervention selected by the parent was not working and that the child was falling behind in his school work, also trigger a call to action but for different reasons to R 5 above. The defining moment for this parent was a sense of urgency and desperation to find a working solution.

‘I remember the day clearly. It was in March this year. We had both been called in for yet another parent teacher discussion. The teacher rocked up with work books, examples of things not done’ [R 4].

Respondent 8 also experienced a call to action when their daughter's behaviour had become intolerably disruptive within the family unit:

‘She had become so disruptive in the family unit...behaviour was just too much...it was getting worse and for the sake of our own sanity and for our younger child, we knew we needed professional help’ [R 8].

For these parents the trigger was again the need to find a working solution based on a realization that the current situation could not continue as it was. In this instance, the process of initiating an intervention was led by both the parents and the teacher in a combined effort to address behaviours which were affecting the family unit as a whole.

In all of the above cases, the motivation to medicate was the results of a trigger which initiated a call to act. As previously stated, initiating stimulant treatment was not a carefully thought through process whereby benefits and risks / costs were weighed up.

#### **4.5 REFLECTIONS AS A CO-CREATOR**

Undertaking this research has meant engaging with the material on more than one level. My position and influence as the researcher has been duly acknowledged at various stages of this write up, both within methodology in the theoretical framework and in the interpretation of data and presentation of findings. I do however feel it necessary to reflect on my position and influence as the mother of a six year old child. Along with those interviewed is acknowledgement that I too am a parent. Unlike those interviewed, my son does not have ADHD and I have therefore (as a parent) not been in the position of having to negotiate treatment options.

In the capacity of a parent, it is difficult to learn your child has problems and is struggling in one area or another. Accepting recognition of issues becomes the first of many hurdles in the process that follows. Determining the next step and then undertaking the responsibility of deciding how best to treat is both overwhelming and emotional. Weighing up pros and cons does not offer a definitive solution and whilst we all know any decision made should be an accurately informed one, access to reliable, reputable sources of information can be problematic. In addition to this, we add the human element to decision making where our beliefs, attitudes and perceptions influence us both consciously and unconsciously.

In no way has my personal position as the parent of a young child compromised any aspect of this research. I do however recognize the need to acknowledge my awareness of the dual role occupied and in reflecting on the interviews themselves I cannot deny the recurring question I ask myself: what would I do if it was me.

The discussion of this chapter has been guided by the specific research questions posed as well as by the identification of dominant, recurring themes. It should however be noted that the themes discussed above are by no means a concrete and finite analysis of the raw material.

## **CHAPTER FIVE:**

### **ANALYSIS AND INTEGRATION OF FINDINGS**

In order to give meaning to the findings presented in the previous chapter, it is necessary to provide an analysis of these findings within the context of theory and in conjunction with consideration of other applicable, current research. In order to best facilitate this, an integration of the findings follows using decision making theory, the Health Belief Model and the Theory of Reasoned Action and Planned Behaviour towards fulfilling the stated aims and objectives of this study.

#### **5.1 THE DECISION MAKING PROCESS**

According to Eysenck (2004), decision making theory and more specifically, descriptive approaches to decision making, assist us in attempting to understand how people approach and make sense of the decisions they face and how they apply approximate techniques to handle complexities that cannot be handled exactly. Descriptive approaches to decision making provide us with increased insight into the cognitive processes that underlie the decision making process with their focus being primarily on the information processing strategies that people use when making judgments or decisions and the role of emotions in the decision-making process.

Eysenck (2004) argues that decision making processes are both reasoning and emotional processes which can be either rational and / or irrational. Eysenck (2004) continues to say that these processes are continuous and are integrated into an individual's interactions with the environment. Glanz (1999) maintains that finding the underlying basis of human decision making is difficult as people cannot always provide realistic accounts of how they make a decision, particularly when there is uncertainty. This is of specific relevance when the decision faced is one related to medical treatments.

In seeking to understand the factors that influence the decision making processes of parents faced with making a treatment decision regarding their ADHD child, findings clearly indicate, first and foremost, that, in line with decision making theory, the decision making process of parents is indeed highly integrated into their individual interactions with their environments, that the process is a continuous one and that understanding the underlying basis of the decision made is difficult as clearly, there is no one, single factor that influences their decision making process and, as state by Glanz (1999) parents are not always able to provide a realistic account as to how they ultimately made their decision.

## **5.2 APPLICATION OF THE HEALTH BELIEF MODEL**

As has been established, understanding decision making processes is a complex, interrelated undertaking; the Health Belief Model (HBM) can however offer a useful conceptual framework providing insight into health behaviour (Glanz, 1999).

The HBM proposes that factors such as beliefs about the consequences of one's problem, the effectiveness of the treatment, and the perceived barriers, all influence health behaviours (Jiang & Johnston, 2010). This model suggests that before an individual takes action, they must decide that the behaviour creates a problem and that moderating or ceasing the behaviour would be in the individual's best interests.

According to Petersen et al (2010), the model maintains that the likelihood of performing a health behaviour is based on an assessment of the following: perceived susceptibility (perception of personal risk), perceived severity (perceived severity of the condition), perceived benefits (perception of the effectiveness of available options) and perceived barriers (perceptions of the potential difficulties in performing the action chosen). This model therefore focuses on two related processes of appraisal: the threat and the behavioural response to that threat.

Incorporating the research findings into the framework offered by the HBM assists us in seeking to understand the decision making process parents undergo in selecting stimulants to treat their ADHD child.

### **a) Perceived susceptibility (perception of personal risk)**

Perceived susceptibility is concerned with the extent to which an individual regards current behaviour as harmful and whether or not moderating or ceasing this behaviour would be beneficial. It is important to note here that an assessment of perceived susceptibility attempts to understand the individual's subjective perception of risk (Glanz et al, 2002).

Findings presented in the preceding chapter confirm that, as per the HBM, before any action is taken, parents must first decide that their child's behaviour creates a problem. This comes in recognising and accepting that the identified issues are negatively impacting on their child's day to day functioning and that it would be beneficial to the child to assist with moderating or ceasing this behaviour.



Findings indicate there are several important factors impacting on a parent's perception of susceptibility. Included in this is: the knowledge parents have of ADHD as a disorder, of etiology, diagnosis and treatments; the information sources parent's access; the parent's willingness to accept or reject initial concerns raised by the child's teacher who, in the majority of cases was the initiator of interventions; the parent's willingness to accept or reject their child's diagnosis as ADHD and the attitudes, beliefs and perceptions parents hold regarding ADHD.

Findings of this research confirm that the information parents have regarding ADHD is limited. To a large extent, parents have a poor knowledge base regarding this disorder. In addition to this, the information sources parents are informed by are neither reliable nor accurate. The information parents have and where it comes from plays an important and largely negative role in informing perceptions of susceptibility.

The relationship between decision-making and state of knowledge is important. With increased exposure to evidence based knowledge, the deliverer of the knowledge attempts to allow the recipient the opportunity to engage in shared decision making with regard to treatment options rather than engaging with a recipient who simply accepts and abides. If the parents were accurately and reliably informed about the typical presentations of the condition, about the demographics of his/her treatment population for this state, about the effectiveness and contra-indications of the recommended treatment as well as regarding the potential duration of the treatment, what to be attentive of in terms of symptom shifts and how to track treatment, one should anticipate less anxiety and more acceptance of the rationale for treatment. In addition to this, reduced anxiety and increased acceptance could be further enhanced if an open line of communication could be afforded by the Health Care Practitioner for parents / caregivers to address concerns during treatment and any subjective fears he/she has towards the use of stimulant medication on their child.

Another significant factor negatively informing perceived susceptibility relates to the parents willingness to accept both concerns raised by teachers and / or the diagnosing medical professional. Findings suggest that in identifying problem behaviours, ADHD is an observer's interpretation of that child. As explained by Parens and Johnston (2009, p.3), many children assessed for ADHD occupy what can be referred to as a 'zone of ambiguity' where physicians, teachers, and parents may disagree as to the display of symptoms, the degree to which functional impairment is experienced and whether or not a diagnosis of ADHD is warranted. In these instances, a child may be diagnosed as having ADHD rather than being referred to as 'simply different or spirited'.

As findings suggest, some parents question whether or not a different teacher would also have interpreted their child's behaviour as problematic. Where parents, teachers and medical professionals do not agree as to the child's behaviour being harmful and / or disruptive, it is unlikely that they will agree on the need to moderate. This has an overall negative impact on perceptions of susceptibility.

Perceived susceptibility is also influenced significantly by the attitudes, beliefs and perceptions parents hold of ADHD. The perceptions parents have regarding ADHD, together with their beliefs regarding varying aspects of the disorder (etiology, diagnosis, treatment), inform attitudes which may either negatively or positively inform a parent's perception of susceptibility. This however relates again to the individual's knowledge of the disorder (as shown in the discussion of findings) as knowledge is a determinant of perceived susceptibility.

#### **b) Perceived severity (perceived severity of the condition)**

Linked to the perception of susceptibility is the perception of severity. The HBM proposes that an additional element related to health decision making includes the perception of severity associated to the risks of leaving a condition untreated and the extent to which the consequences of this are undesirable (Glanz et al, 2002).

Danciu (2011, p.2968) writes: 'In addition to its central traits, [ADHD] can lead to a series of associated, secondary traits, such as: disorganization; poor social relations with [siblings] and children of the same age; aggressive behaviour; low self-esteem and deficient self-knowledge; self-stimulation behaviour; daydreaming and absentmindedness; coordination deficits; memory problems [and] persistent obsessive thoughts'.

Brinkman et al (2009, p.581) state ADHD results in the impairment of academic, social, interpersonal and family functioning. When studied across time, children diagnosed with ADHD are at higher risk for learning, behavioural, and emotional problems throughout childhood and adolescence (Doggett, 2004). In addition to this, ADHD is also associated with several comorbid conditions and disorders such as mood disorders, disruptive behaviour disorders and learning disabilities (Antshel et al, 2011).

Left undiagnosed and untreated, ADHD negatively impacts on an individual's 'learning capacity, [their] family life, education, social interaction' and may lead to depression and / or anxiety (Danciu, 2011, p.2968).

The effects of ADHD are well established to be pervasive across a variety of settings including scholastic performance, academic achievement, vocational success, family relationships and social-emotional development (Doggett, 2004).

In terms of perceptions of severity, this is identified as being negatively influenced by the lack of knowledge parents have regarding ADHD and the resulting lack of insight regarding its severity. Perceptions of severity have the potential to be positively influenced by the nature of the parent / teacher relationship as well as by the relationship the parent's have with their child's doctor or the medical professional consulted. Green and Kreuter (1999) believe fear to be a powerful motivator in considerations of severity. Fear-based messages from teachers, other parents, the media and medical professional are significant influencers in terms of perceived severity.

Perceived severity warrants a dynamic of understanding of how parents perceive the condition arises as well as consideration of the circumstances that may or may not influence parents perceived susceptibility: Has this condition been adequately and / or convincingly diagnosed, are stimulants the only evidence based treatments available and could any other co-morbid or primary condition explain the presentation of symptoms are all relevant here.

### **c) Perceived benefits (perception of the effectiveness of available options)**

Gorin and Arnold (1998) explain perceived benefits as the belief an individual has regarding the effectiveness of various available alternatives in reducing threat.

According to the Reiff (2011) stimulants are the most frequently prescribed medications for ADHD - paediatric groups endorse the use of stimulants as first line therapy in most children with ADHD aged 6 – 12 years, estimating that 80% of these children will respond to stimulants. Methylphenidate is the psycho-stimulant that is most frequently prescribed in the management of ADHD in South Africa and it is considered to be the first-line medication in the treatment of ADHD (Truter, 2009). In treating ADHD, psycho-stimulants in particular are now readily available and are being prescribed with increasing frequency (Christensen-Szalanski and Northcraft, 1985).

In their 2011 journal article, Wender, Reimherr, Marchant, Sanford, Czajkowski and Tomb reported on their study examining 'the efficacy of methylphenidate in the long-term treatment of ADHD in adults on both ADHD symptoms and, economic, educational, vocational, social, extended family, marital, and

parental functioning' (2011, p.36). Highlighting a decrease in symptom severity, life changing improvements in social functioning and no drug abuse or tolerance, the authors concluded that 'a long-term trial of methylphenidate in adults with ADHD produces extremely large, life-altering changes in symptoms and in work and social functioning' (Wender et al, 2011, p. 43).

According to Reiff (2011), with effective stimulant medication treatment, children with ADHD are better able to manage academic work and social interaction, attend to behaviour modification techniques, and follow rules. Reiff (2011) advocates that by helping a child focus, stimulants lay the groundwork for being able to respond better to behaviour management techniques, academic instruction, and other attentional demands - research has shown that such other treatments are more likely to work if the child is also taking stimulants (Reiff, 2011).

There is little doubt that stimulants are presented to parents as a treatment option with significant benefits. Findings overwhelmingly support the literature in illustrating that stimulants are prescribed as first line treatment for ADHD. The benefits of stimulants are promoted by teachers, friends, other parents and medical professionals – parent's are often referred to other parent's whose children have flourished since taking stimulants. In addition to this, there is empirical evidence supporting the efficacy of stimulants.

Findings show that, following the recommendation of prescription medication, parents engage in a risks v benefits assessment where the benefits of taking stimulants was weighed up against the risks. For all parents, the risks associated to medicating were related to perceptions of harming their child by medicating long term. All participants were guided ultimately by attempting to decide what was best for their child. The perceived benefits of medicating and the offer of a solution to an accepted problem was pitted against assessing the health implications related to stimulant medication. For the two respondents who opted for natural supplements before 'resorting' to medication, the costs/risks of stimulants use outweighed the benefits, hence the decision was not to initiate stimulant treatment. Two additional important factors influencing this assessment / weighing-up process include the following: firstly, the extent to which parents perceive the condition to be accurately and / or convincingly diagnosed – linked to this is the level of confidence parents may or may not have in the opinion and recommendation of the medical professional they are consulting. Findings show that where the prescribing doctor was regarded as the expert, the parent willingly accepted the underlying endorsement the doctors gave of stimulants. Secondly the personal beliefs, attitudes and perceptions parents hold regarding drug use (the taking of medication) also influences a cost/benefit assessment.

**d) Perceived barriers (perceptions of the potential difficulties in performing the action chosen)**

Perceived barriers considers factor that parents perceive as barriers to undertaking a specific action. This has been described as a process whereby individuals weigh up the benefits of an action and the extent to which it is a viable undertaking (Glanz et al, 2002). Several factors were perceived as barriers to undertaking stimulant treatment: Although the safety of short-term methylphenidate use in clinical trials has been relatively well established, repeated and long-term use of psycho-stimulants is less clear. In this respect, data is limited: There are no guidelines relating to the specifics of withdrawal for discontinuing long-term use of stimulants and the relationship between long-term use of medication during childhood and future risk of substance abuse is also an area of concern (Ashton et al, 2006). Findings indicate that parent's are not comfortable with placing their young child on long term medication, particularly because long term safety has not yet been established.

Despite it being beyond the scope of this study, it would be interesting to discuss the stigma imposed by society regarding efficacy/dangers of using medication and how this has informed perceptions regarding personally making such decisions. It would be interesting to explore what informs parents to have more trust in options such as over the counter supplements that profess positive benefits yet lack the longevity of symptom management. These decisions such as the latter surely don't take as much reasoning as the one to use stimulant medication.

In addition to this, findings suggest that parents continuously wrestle with several obstacles. These include being unconvinced as to the diagnosis of their child [there is still debate as to whether ADHD is over diagnosed or under-diagnosed (Reiff, 2011)] raising concerns as to whether or not their child really requires the medication, contemplating the side effects of the medication (loss of appetite, insomnia, personality changes, aggression), wanting to explore alternatives to stimulant treatment first (in the case of two respondents) and the information parents have and where it comes from. Several respondents also referred to the cost of medication being a potential barrier but that it was a necessary expense that would just have to be incorporated into the monthly budget. Other barriers include: poor parent / teacher communication; denial of a problem and / or lack of confidence in the diagnosis; lack of support from friends and family members (who have their own subjective opinions); stigma, negative social media reports and a desire not to rely on medication as a solution.

Parental beliefs, attitudes and perceptions of ADHD are also significant perceptual barriers and again is the influence of information – inaccurate, misleading information relating to ADHD, etiology, diagnosis and treatment may also act as an impediment to undertaking recommended action.

#### **e) Cue to action**

In addition to the above, the HBM considers factors which prompt action, understanding behaviour to be triggered by a ‘cue to action’ where health-related decisions are triggered by environmental cues (Petersen et al 2010, p. 22). Findings indicate that an important element as a factor motivating use of medication in ADHD treatment is a defining moment where the parent was motivated to act as a result of them feeling sufficiently threatened by their child’s behaviour and recognising that stimulant intervention will produce the ability for their child to behave differently. In these cases, the decision making process was not careful deliberation of perceived susceptibility, severity, benefits and barriers, rather, the decision was motivated by threat and the need for immediate intervention.

#### **f) Self-efficacy (perceptions that one has the ability to successfully perform an action)**

Gorin and Arnold (1998) explain self-efficacy as the confidence an individual has in their ability to successfully implement the required action to produce the desired outcome. Positive influences on self-efficacy include accurate, reliable information – the parent whose child was diagnosed by a psychologist reported having accurate information regarding diagnosis in particular, instilling a sense of understanding and empowerment. Support offer by teachers and other parents also contribute significantly to self-efficacy, included in this is positive feedback from teachers regarding behaviour modification. Self-efficacy is also positively influenced by having the necessary finances to purchase the necessary medication – for some parents this was enabled through private medical aids.

The HBM is a useful framework for gaining insight into decision making processes, particularly as it incorporates a common-sense approach. It does however encourage a tendency to over-simplify health-related decisional processes. In addition to this its broadly / generally defined theoretical constructs are not necessarily applicable to all circumstances. In unpacking decision making, one cannot exclude individual motivational factor that impact on decision making. Incorporating the Theory of Reasoned Action is therefore important as the relationship between behaviour and personal, subjective aspects are taken into account.

### **5.3 APPLICATION OF THE THEORY OF REASONED ACTION**

The Theory of Reasoned Action attempts to understand the relationship between attitudes and behaviour. Ajzen and Fishbein (1980) believe behavioural intentions are derived from two parallel cognitive processes. The first involves consideration of the individual's own attitudes towards the behaviour and the second involves consideration of the relevant social norms. Attitudes are concerned with beliefs about the behaviour under consideration and comprise two elements: an appraisal of the likelihood that significant others would wish the individual to engage (or not) in the behaviour under consideration, and their motivation to comply with these expectations.

Brinkman et al (2009) describe the context of decision making as one containing many parent stressors. Included in these are: self doubt, daily struggles both at home and at school, parental conflict with one another, self blame, having parenting skills challenged and carrying the emotional burden of having to make a decision. In addition to this, Brinkman et al (2009) recognize the decision making process as one that is regularly revisited where parents experience ongoing doubt and uncertainty regarding their decision to medicate.

Results of this study confirm that 'decisions around the use of stimulant medication for children with ADHD are difficult'. Themes of ambivalence and confusion; the influence of the media; deciding against medication and deciding for medication emerged (Jackson and Peters, 2008, p.2725). One cannot ignore the multiple influences of an individual's own attitudes, perceptions of the attitudes of significant others, and perceived behavioural control, on the intention to perform health behaviours.

Working through the transcribed interviews, it is clear that each individual interviewed had their own unique experience. Every parent described their differing individual encounters with their child's teacher, with the diagnosing medical professional and with significant others. These experiences were further differentiated as a result of the personal beliefs, attitudes and perceptions parents held. Findings indicate that a parent's beliefs, perceptions and attitudes regarding teachers, medical professionals, ADHD as a disorder and modern society, are reflected in their decision making process.

In addition to this, findings report parents feel a measure of pressure to medicate with one of the sources of this pressure being that stimulant treatment is perceived as a social norm. a second source of pressure comes in the form of persuasion from significant others (peers, teachers and doctors), to 'just try it'. These have been identified as significant factor influencing the decision making process.

## **5.4 CONCLUDING COMMENTS**

An analysis and integration of findings in conjunction with a framework offered by theoretical models, can offer us insight into the factors that influence a parents decision to treat their ADHD child with stimulants.

Perceptions of susceptibility, severity, benefits barriers and self-efficacy are significant factors which parents wrestle with in having to make a treatment decision for their child diagnosed with ADHD. Analysis also confirms that a trigger or cue to act contributes significantly as a motivator to medicate.

Integration of findings does however clearly illustrate that no one single model can explain health behaviours. The decision to implement a treatment intervention is the result of many varied, often unpredictable, interrelated factors that do not necessarily follow a causal, well explained step-by-step process.

Guided by specific research questions and supported by theory, the analysis of the data presents us with some significant findings from which some important conclusions can be drawn.

These specific conclusions in relation are presented in the following chapter.



## **CHAPTER SIX: CONCLUSIONS AND SUMMARY**

### **6.1 SUMMARY OF THE RESEARCH FINDINGS**

An interpretive thematic analysis technique was employed to give meaning to the rich qualitative data collected. Dominant and / or recurrent themes, guided by the stated research questions, were identified across the semi-structured interviews conducted.

The discussion and analysis work towards responding to two specific research questions. These are stated as:

1. What factors influence a parents' decision making process when considering various treatment options for their child diagnosed with ADHD?
2. What factors motivate a parents' decision to select and initiate psycho-stimulant medication as the primary method of treatment for their ADHD child?

An analysis of the transcribed interviews suggests that the factors that influence the decision making process include:

1.
  - a) The knowledge parents have of ADHD as a disorder and the information sources parents draw on.
  - b) The substantial role the child's teacher play in the initial identification of issues and in providing ongoing feedback as to the effectiveness of the treatment selected.
  - c) The extent to which parents either accept or reject their child's ADHD diagnosis.
  - d) The beliefs, attitudes and perceptions parents hold regarding all aspects of ADHD.

An analysis of the transcribed interviews suggests that the factors that motivate a parent to choose medication in treating their child diagnosed with ADHD include:

2.
  - a) The limited selection of alternative products and supplements, the inconsistent results these alternative produce and the extent to which alternative treatment approaches are endorsed by medical professionals.
  - b) The faith parents have in the expert opinion of the prescribing doctor.
  - c) Feeling under pressure by teachers, doctors and peers to medicate.
  - d) A specific defining moment triggering a cue to action.

## **6.2 CONCLUSIONS**

In light of the findings discussed the following conclusions can be stated:

- There are many diverse factors that influence both the decision making process of parents as well as a definitive decision to choose psycho-stimulants as treatment from their ADHD child.
- Parents make ADHD treatment decisions based on misinformation from unqualified sources.
- Diagnosis of ADHD remains contentious as it is viewed as an observers' interpretation of their experiences with the child. This raises questions as to ADHD possibly being incorrectly diagnosed and therefore unnecessarily treated with stimulant medication.
- The beliefs, attitudes and perceptions parents hold of ADHD and its treatment options play a role their decision making process. These beliefs, attitudes and perceptions may be related to the misinformation parents have regarding aspects of ADHD.
- There is no single factor that can be identified as a motivator to medicate.

- The decision to initiate stimulant treatment is both complicated and intricately related to the individual experiences parents have with their children, with their child's doctor, with their child's teacher and with alternative treatments.

### **6.3 CONTRIBUTIONS MADE BY THIS RESEARCH**

This research is intended to offer a contribution within the area of better understanding the experiences of parents' when faced with ADHD treatment decisions. In addition to this it offers a contribution in offering insight into the factors that motivate a decision to medicate. These areas are both substantially under researched.

Identifying and understanding the factors that motivate treatment decisions can assist physicians and other healthcare professionals in addressing the concerns parents have in managing ADHD. In addition to this, an awareness of the factors influencing parental decisions regarding medication magnifies the important role healthcare professionals have in providing accurate and current information to parents and families when they are faced with making decisions about treatment for their child with ADHD.

An important contribution of this research is to highlight the critical role information plays in many areas – not only in decision making but also as an influencing factor on beliefs, perceptions and attitudes. Psycho-education, in relation to the stakeholders of diagnosing ADHD (psychiatrists, pediatricians, psychologists) as well as to parents and teachers, needs to be implemented and a follow up of its effects needs to be measured in relation to the findings of this study.

This research is also offered as a guide to parents to assist with exploring the complexities relating to ADHD treatment decision making.

### **6.4 LIMITATIONS OF THIS RESEARCH**

It is acknowledged that the current sample is highly specific in terms of race, culture and socioeconomic status. An implication of this is that not all experiences may be similar with samples of different identity markers. For example: Jasmin Kooverjee (2006) investigated factors that mediate treatment adherence to psycho-stimulant therapy in treating ADHD. One of her findings was that due to homeopathic medication not being covered by medical aid, parents felt forced to use psycho-stimulants which are covered by medical aids – with homeopathic treatments costing the same, if not more than prescription medication yet not covered by medical aid, financial pressure meant opting for that which medical aid did cover.

Cost of medication and finances were not identified as significant issues by the parents interviewed in this research.

Another limitation is that the small sample size and the qualitative nature of this research does not allow for generalizations to be made. This was however never the intention of this research but, as mentioned in the methodology chapter, more interviews could have been conducted.

## **6.5 RECOMMENDATIONS FOR FUTURE RESEARCH**

Current ADHD treatment research focuses largely on psycho-stimulants. Research exploring other medications, not stimulants, Strattera for example, and alternative treatment approaches should be undertaken as the lay persons knowledge of treatment is currently dominated by that of Ritalin and / or Concerta.

Longitudinal studies which incorporate the retrospective experiences of adults who were diagnosed ADHD and treated for the condition are in the minority. Retrospective, longitudinal studies would provide us with valuable insight into a many aspects of ADHD such as specific difficulties experienced, effects of treatment / non-treatment and hindsight recommendations.

Research into how best to provide parents and teachers with reliable, accurate information relating to ADHD is also highly recommended.

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### **Relevant unpublished research and other sources of information**

- Kooverjee, J. (2006). *An Investigation Into The Determinants Of Treatment Adherence To Psychostimulant Therapy Amongst Grade 3-6 School Children With Attention Deficit Hyperactivity Disorder (ADHD) In A Selected Pediatric Practice In The Durban Metropolitan Area*. University of KwaZulu-Natal (Howard College). Unpublished thesis.
- Matthias, C. (2012). *Children with attention deficit hyperactivity disorder needs and experiences of parents/caregivers receiving services from a public sector hospital*. Unpublished thesis.

## **APPENDIX**

## 1: ETHICAL APPROVAL



23 November 2012

Mrs Elspeth Cornell 931323143  
School of Applied Human Sciences – Psychology  
Howard College Campus

Dear Mrs Cornell

Protocol reference number: HSS/1272/012M

Project title: A qualitative study exploring factors that mediate parents' decision making in selecting psycho-stimulant therapy as the preferred treatment for their child diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD).

### Expedited Approval

I wish to inform you that your application has been granted Full Approval through an expedited review process.

Any alteration/s to the approved research protocol i.e. Questionnaire/Interview Schedule, Informed Consent Form, Title of the Project, Location of the Study, Research Approach and Methods must be reviewed and approved through the amendment/modification prior to its implementation. In case you have further queries, please quote the above reference number. Please note: Research data should be securely stored in the school/department for a period of 5 years.

I take this opportunity of wishing you everything of the best with your study.

Yours faithfully

Professor Steven Collings (Chair)

/px

cc Supervisor Mr Sachet Valjee  
cc Academic leader Professor JH Buitendach  
cc School Admin. Mr Mondli Ngubane/Ms D Hattingh

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Founding Campuses: ■ Edgewood ■ Howard College ■ Medical School ■ Pietermaritzburg ■ Westville



## 2: LETTER OF INTRODUCTION

Dear Potential Participant,

I am a postgraduate student completing my master's degree in counseling psychology at the University of KwaZulu-Natal, Howard College in Durban. Completing a research dissertation is part of the requirements for the completion of this degree. I am undertaking research that seeks to investigate what factors determine a parents' decision to use psycho-stimulant medication as the primary method of treatment for their ADHD child and their experiences throughout this decision making process.

The proposed title for this is: *A qualitative study exploring factors that mediate parents' decision making in selecting psycho-stimulant therapy for their ADHD child.*

To participate in this study you must be: **a)** the primary caregiver of a child. **b)** This child must be clinically diagnosed with Attention-Deficit/Hyperactivity Disorder (ADHD) with any / all subtypes. **c)** This child must be currently receiving psycho-stimulant medication, prescribed by a doctor or specialist towards treatment of this disorder. You have been identified as possibly fulfilling these criteria.

Data collection for this study will be in the form of a semi-structured interview conducted by myself. The interview will take approximately one hour and I will be asking your permission to record it. This is to ensure accuracy in its transcription. All participant information will be kept confidential and all those involved in this study will remain anonymous. This will be ensured by the use of pseudonyms to protect individual identity or by being referred to as participant one or two etc. In addition to this, your name will not be asked for at any stage and no information will be required that identifies you or your family members in any way. Should you request it, a copy of your transcribed interview can be available and as well as the research findings and recommendations. All research data collected will be kept for a period of at least five years. Confidential information relating to this research will be stored in a secure location. This will be overseen by my supervisor. Once the period of five years is fulfilled, all information will be shredded.

Although your participation will be greatly appreciated, you are not obligated to participate in this research. Participation is strictly voluntary. You may choose to withdraw from this research at any stage, without prejudice. Participation will however be of no benefit to you – monetary or otherwise. It is necessary for me to obtain your consent to participate in writing. Should you agree to participate, please could you complete and sign the declaration form enclosed and send it back to me within 10 days. Alternatively, I can arrange to collect it from you. Should you agree to participate, I will be contacting you to arrange a suitable time, date and location for the interview. For more information, please feel free to contact either myself or my supervisor at the address provided below.

Thank you for your consideration in contributing your time to assist with this important study.

Yours sincerely,

Elspeth Cornell  
University of Kwazulu-Natal  
Howard College Campus  
School of Psychology, Durban  
Email: elscornell@gmail.com

Supervisor: Sachet Valjee  
University of Kwazulu-Natal  
Howard College Campus  
School of Psychology, Durban  
Email: valjees@ukzn.ac.za



### 3: CONSENT FORM

#### DECLARATION:

I ..... (Full names of participant)  
hereby confirm that I have read and understood the contents of the letter of introduction.

In addition to this, I understand the nature of the research project, and I consent to participating in it. .

I understand that I am at liberty to withdraw from the project at any time, should I desire to do so.

SIGNATURE OF PARTICIPANT

DATE

.....

.....

**If you wish to obtain additional information on your rights as a participant, please contact Ms Phumelele Ximba, Research Office, UKZN, on 031 360 3587.**

## **4: INTERVIEW GUIDE**

### **Closed ended questions**

- What is your child's current age?
- Is your child a boy or a girl?
- What would you say is their general state of health?
- When was your child diagnosed with ADHD?
- What subtype have they been classified as having?
- What was their age at that time?
- Who was your child diagnosed by?
- How long after diagnosis did you start treatment?
- What was that initial treatment?
- When did you start psycho-stimulant treatment?
- What was prescribed and in what dose?
- What medication is currently being taken and in what dose?

### **Open ended questions**

1. What is your understanding of ADHD?

**Probes:** What is your overall knowledge of the disorder? Are you familiar with etiology, how it is diagnosed and treatment options?

2. When were you first made aware of a possible problem with your child?

**Probes:** Who / what alerted you to any issues? What was your course of action? Who formally diagnosed your child? How was this diagnosis reached? Was this process adequately explained to you? What was your reaction to the diagnosis? How did you feel? What were your concerns?

3. What treatment options were explained to you?

**Probes:** What is your knowledge of available treatment options? How were these explained to you? Were you given any reading material to review?

4. How did you assess the treatment options?

**Probes:** What were your thoughts and attitudes towards the treatment options? Did you consider costs? How did you feel about medication and its long term use?

5. How did you approach making a treatment decision?

**Probes:** Who did you involve in assisting with making a treatment decision? Who was responsible for making the final decision? What social support (if any) did you experience?

6. Specifically, what factors did you consider when making a treatment decision?

**Probes:** What issues were topics of discussion in considering treatment options? Who participated in these discussions? What additional sources of information or input were sought? Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting psycho-stimulant medication as the preferred treatment option?

7. What were your experiences following on from this treatment?

**Probes:** What have been your experiences with using psycho-stimulants? What have been the effects and outcomes? In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?

## 5: INDIVIDUAL INTERVIEWS

The pages that follow contain the transcribed interviews of each of the ten participants in this study. To ensure anonymity each has been referred to as respondent 1, 2, 3 and so on.

Italics represent questions and probes of the researcher.

### Respondent 1:

*What is your child's current age?* 5

*Is your child a boy or a girl?* A boy

*What would you say is his general state of health?* Good with the odd cold

*When was your child diagnosed with ADHD?* In April 2012

*What subtype has your son been classified as having?* Hyperactivity and Impulsivity

*What was his age at that time?* 5

*Who was your child diagnosed by?* A specialist pediatrician

*How long after diagnosis did you start treatment?* The next day

*What was prescribed and in what dose?* Ritalin, 10mg daily

*What medication is currently being taken and in what dose?* Ritalin, 5mg daily

*What is your general understanding of ADHD?*

I understand it is a medical condition where the signals from the brain get mixed up and don't flow as smoothly as they should. Oh, and that it is most often found in children when they start school.

*Are you familiar with what causes ADHD?*

I have to admit that I don't know very much about ADHD. I am not that sure about what causes it. The Paed explained to my husband and I that it can be inherited and I think I have read somewhere that the food a child eats can also influence their behaviour.

*What do you know about how ADHD is diagnosed?*

Well, I know it is diagnosed by doctors and that doctors seem to rely on input from the child's teacher, from consulting with the parents and from observing the child in the consultation room.

*What do you know about treating ADHD?*

Nine times out of ten, it's Ritalin although I do see loads of products on the shelves in Diskem these days claiming to treat ADHD. Apparently Biostrath is meant to help with concentration but I don't know anyone who says those natural products actually work.

*When were you first made aware of a possible problem with your child?*

I would say about 2 or 3 months into the school year. Yes, Grade R started mid-January and our first visit to the specialist was in March.

*Who / what alerted you to any issues?*

Definitely the teacher. No one else had ever mentioned anything about his behaviour before.

*What was your course of action?*

Well, we started getting notes in my son's homework book about things he had done, it seemed like he was just getting into trouble all the time. We met with the teacher and she asked us please to take him for an assessment with Dr. XXX so that's what we did.

*Who formally diagnosed your child?*

The specialist pediatrician.

*Do you recall how the diagnosis was reached?*

Well, he asked us loads of questions about all sorts of things and was continually watching John throughout the consultation. Before coming to the appointment, we had been asked to fill out this paperwork, a Connor's Rating Scale. In our appointment, he showed us one our son's teacher had also completed.

*Was the process of diagnosis adequately explained to you?*

Not at all, we kind of just went along with things, doing what we were told before the appointment and then when in the appointment.

*What was your reaction to the diagnosis? Do you remember how you felt or what some of your concerns were?*

My heart sank, my eyes filled up with tears, I was angry, I definitely did not want my son on hectic medication for the rest of his life. And it was like everyone just decided this – as much as I said my son doesn't behave the way the teacher describes him at home, it was like no one believed me. I felt like everything was out of my control. Even now, I don't think my child has ADHD and I don't like that label because that's really what it is...an easy way of saying a child is a little more challenging to deal with.

*What treatment options were explained to you?*

It was suggested that we go on a trial of Ritalin.

*What is your knowledge of available treatment options?*

Just that it is either Concerta or Ritalin that is prescribed and that there are some herbal supplements which don't really work very well.

*How were these different options explained to you?*

They weren't really. It wasn't specifically explained *how* Ritalin and Concerta work. And no suggestions around supplements were made.

*Were you given any reading material to review?*

No.

*What were your thoughts about the treatment options?*

Honestly, very negative. I still resent the fact that my child takes a tablet every day to restrict his behaviour. And I feel like it will be forever. And it's obvious it is a serious drug as you need an original script every time and it is very strictly monitored.

*Did you consider the cost of the medication?*

I felt like we didn't have a choice, like it was just something we would have to accept as a monthly expense.

*How do you feel about medication and its long term use?*

It's awful, I think it's ridiculous to take something indefinitely. I mean, it can't exactly be good for you.

*How did you approach making a treatment decision?*

If you are asking how I came to the decision to use Ritalin, my response to that is there wasn't really a decision to make. I mean, it wasn't like we had a choice.

*What do you mean?*

Well, the teacher is telling me how badly behaved my child is and how others in class are not wanting to play with him, this specialist is sitting behind his desk telling me what my son needs and basically writing out a script so where's my decision in that?

*Who did you involve in assisting with making a treatment decision?*

No one really. My husband and I left the consult kind of overwhelmed by everything. We talked a little in the car but it wasn't like we were deciding should we / shouldn't we.

*Who was responsible for making the final decision?*

As I said, it wasn't this big decision we pondered over for ages. It was kind of like a foregone conclusion – you take your child to the doctor, they make a diagnosis, they write you a script and off you go.

*What social support (if any) did you experience?*

We didn't really discuss it much with others. I told a couple of friends and they didn't pass much comment at all.

*Specifically, what factors did you consider when making a treatment decision?*

I mostly just worried about what effect the meds would have on my boy.

*What issues were topics of discussion in considering treatment options?*

None really, like I said, it was just taken as done that we would get what was on the script and start the next day.

*Who participated in these discussions?*

Just me and my husband and the doctor I suppose.

*What additional sources of information or input were sought?*

I just looked up on the internet the side effects of Ritalin – of course that made me feel even worse.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting medication as the preferred treatment option?*

I can't say there was any defining moment. I mean, it's not like we were presented with all these options and had to make a choice. It was more like: this is the issue, this is the treatment. I seriously didn't feel like there was a choice or decision to be made. It was like it had all been decided already.

*What were your experiences following this treatment?*

We started with the 10mg the next day. Feedback from the teacher was that he was like a different child and suddenly he was this star in class. He did however become very quiet and withdrawn, like out of it which is why we went back to the doctor and he lowered the dose. This improved things a bit.

*What have been your experiences with using Ritalin?*

I feel like Ritalin is hailed as this wonder drug that solves everything but I feel like it changes my child's personality and makes him someone he is not.

*What have been the effects and outcomes?*

Well, he doesn't get into trouble at school so much anymore but I don't think he is happy – he's not himself, he's not open and carefree like he was. Apart from making the teacher's life easier, I don't see any great benefit. I am not sure how long he will stay on them.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

When I look back, I feel a bit like I was bullied. I felt a loss of control in the situation. At the end of the day, it comes down to what the specialist and the teacher say. I am sorry I just went along with everything. It's not like we had these issues when I was a child so why now? Why do doctors and teachers want to put every Joe Soap on Ritalin. And what about the long term side effects? I don't think anyone knows really what those are. I generally find it difficult to do something I am not committed to, and I am not committed to this. I think it's important that you as the parent are onboard with whatever treatment is offered. And that's not just in this case with this medication, it's generally, with any treatment options. Also, I felt quite overwhelmed and pressurized by both the teacher and the doctor. I just didn't feel like I was making a decision. I am still upset about this.

Respondent 2:

*What is your child's current age?* 7 turning 8 in one week

*Is your child a boy or a girl?* A girl

*What would you say is her general state of health?* Generally very good

*When was your child diagnosed with ADHD?* Towards the end of her Grade one year

*What subtype has your daughter been classified as having?* Inattentions, but she can also be very impulsive

*What was her age at that time?* 7

*Who was your child diagnosed by?* Our GP

*How long after diagnosis did you start treatment?* I would say within a week

*What was that initial treatment?* Concerta was prescribed, initially the 20 something dose

*What was prescribed and in what dose?* Concerta, I think it's either 27 or 28mg

*What medication is currently being taken and in what dose?* Concerta 36mg daily

*What is your general understanding of ADHD?*

That it is a disorder usually noticed in young children where their behaviour and their ability to focus is affected. Oh, and that it can either be inattention or hyperactivity or both.

*Are you familiar with what causes it?*

Not at all.

*What do you know about how it is diagnosed?*

I think it is mostly teachers first who notice how a child is coping, and how their behaviour compares to others and generally if they are kind of normal or not in what they do, how they do it and how long it takes. Then parents are asked to see their doctor and the doctor pretty much listens to how the child is described and decides from there what to do.

*What do you know about treating ADHD?*

That is most effectively treated with either Ritalin or Concerta. I think Ritalin is more for the hyperactive, impulsive ones and Concerta for those with poor focus and concentration.

*When were you first made aware of a possible problem with your child?*

It was into the second term of Grade one. The teacher called us in and said our daughter was really slow finishing work, that she was very easily distracted and always lost stuff.

*Who / what alerted you to any issues?*

Like I said, the teacher.



*What was your course of action?*

At first we didn't really change much. We just encouraged Sarah to think about what she was doing, to try and remember stuff. We made a real effort to sit with her doing homework.

*Who formally diagnosed your child?*

Our GP

*How was this diagnosis reached?*

We made an appointment to see our family GP and basically filled him in as to what the feedback from the teacher was. We also told him of our struggle to get Sarah to do things, how frustrating she can be with losing things, starting something and not finishing it.

*Was this process of diagnosis adequately explained to you?*

Sort of. Our GP spent loads of time with us and we asked lots of questions. .

*What was your reaction to the diagnosis? How did you feel? What were your concerns?*

To be honest, it was mixed as I didn't really want my daughter on medication daily but I was also excited to see how the meds worked. I didn't feel like it was the end of the world or anything like that, more just a sense of, ok, so what do we do about it.

*What treatment options were explained to you?*

It was suggested that we try Concerta if we were happy to and to come back in a month to discuss how the month had been.

*What is your knowledge of available treatment options?*

I do know there are some herbal or nature options but I don't think those really do much. Then of course Ritalin and Concerta. I believe there is a Ritalin generic.

*How were these different treatments explained to you?*

We really just talked about Concerta and that some studies show what kids eat can influence behaviour so watching sugar and processed foods with loads of preservatives should be avoided.

*Were you given any reading material to review?*

We were referred to some websites.

*What were your thoughts on the different treatment options?*

Do you mean what did I think of them?

*Yes, what were your thoughts and attitudes towards the treatment options?*

Pretty neutral I would say. I just kind of saw it as I would any medication, like a course of antibiotics – if that's what it takes, then so be it.

*Did you consider costs?*

Well, at the time we had no idea what Concerta cost so no, not really, and then it just became something else we had to pay for every month.

*How do you feel about medication and its long term use?*

I don't really think about it that much. I don't know what will happen in the future or how long it will be needed, also, it works its way through the body quite quickly so it's not like it builds up.

*How did you approach making a treatment decision?*

Well, after that long consult with the GP, we went home with the script and talked about everything the doctor had said. We weighed up the pros and cons then came to the conclusion just to try it and see what happens.

*Who did you involve in assisting with making a treatment decision?*

We talked a lot between ourselves and I asked some of my friends whose kids also take Concerta about their experiences.

*Who was responsible for making the final decision?*

Both my husband and I.

*What social support (if any) did you experience?*

Well, I actually didn't realize how common it is – so many kids these days are either on Ritalin or Concerta. That made me feel so much better. People really didn't bat an eye lid. Most said we would notice a huge difference.

*Specifically, what factors did you consider when making a treatment decision?*

I was concerned about side effects, especially since everyone told me my child would stop eating. I thought a lot about if it was really necessary.

*What issues were topics of discussion in considering treatment options?*

We talked about moving to the remedial unit within the school for our daughter to get more focused attention. Also, we discussed supplements – you know, all those you see on the shelves in pharmacies. And we also thought maybe she would just suddenly mature and all the concentration and distraction would go away.

*Who participated in these discussions?*

Me and my husband and I also talked a lot to my close friend.

*What additional sources of information or input were sought?*

Definitely the experiences of friends. I did read some stuff on the net but I wanted to hear from people I knew.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting Concerta as the preferred treatment option?*

Well, we spent the week following our doctors appointment talking to each other and to friends and the doctor had told us that the script was only valid for a month I think. One day we just said to one another, let's just try it, you know, you won't know unless you try, so we did. I collected the script that same day.

*What were your experiences following on from this treatment?*

We noticed a difference pretty much immediately with focus and attention and getting things done, managing to keep up with the rest of the class. We also noticed the lack of appetite.

*What have been your experiences with using Concerta?*

Very positive. They are like a wonder drug. They seriously do their job. The difference in my child on and off meds is like day and night. She has lost weight, she seemed to lose a lot, quickly but this has sorted itself out now and she is definitely not thin or anything like that. I also have to give it early in the morning as it keeps my daughter awake for ages at night.

*What have been some of the effects and outcomes experienced?*

As I said, really just very positive. So much more gets done and my child feels so much better about not always finishing last or struggling to keep up. The benefits have been huge.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

I think just to really consider what is in the best interests of your child and that sometimes you have to give things a go before making a decision. I definitely don't have any regrets.

Respondent 3:

*What is your child's current age?* He has just turned 10

*Is your child a boy or a girl?* A boy

*What would you say is their general health status?* Prone to colds but generally in good health

*When was your child diagnosed with ADHD?* I would say about a year ago

*What subtype have they been classified as having?* Inattention

*What was their age at that time?* About 8 I guess

*Who was your child diagnosed by?* Our GP

*How long after diagnosis did you start treatment?* The next month

*What was that initial treatment?* ADDAWAY and Biostrath.

*When did you start medication?* About 7 months after trying the natural supplements

*What was prescribed and in what dose?* At the initial consult Ritalin was prescribed but we first tried the natural supplements then started on Ritalin

*What medication is currently being taken and in what dose?* Right now, Concerta 36mg daily

*What is your general understanding of ADHD?*

ADHD is a condition which means you lack concentration and focus, you are easily distracted, constantly lose and forget things and take a long time to complete things.

*Are you familiar with what causes it?*

No, not really to be honest.

*What do you know about how it is diagnosed?*

That a doctor relies on feedback from a teacher as to how the child is performing in class. They also ask the parents about the child's behaviour at home and from there try and get a picture of what the child is like and if there are any issues.

*What do you know about treating ADHD?*

Well, most kids seem to get put on medication, usually Ritalin but also concerta. Some can be treated with careful diet, you know, like limiting sugar and preservative. And sometimes supplements seem to work, like the stuff they promote in health stores but I guess it depends on how severe their issues are.

*When were you first made aware of a possible problem with your child?*

When David started grade two, about a month in, the teacher called us in to talk about him not really keeping up in class and taking long to finish things. It was mostly him being distracted and very disorganized.

*Who / what alerted you to any issues?*

Definitely our son's teacher.

*What was your course of action?*

Not a lot. We spoke to our son about putting more effort into his work and got all his books up to date and generally trying to be more organized.

*Who formally diagnosed your child?*

Our GP.

*How was this diagnosis reached?*

Well, the teacher called us in again about a month later with all the same issues. She asked us please to see our doctor so we did. She felt really strongly that as a result of the distraction and disorganization, he was just not coping and that we needed to discuss this with our GP.

*Was this process of diagnosis adequately explained to you?*

Yes. Well, it was never really specifically explained to us that this is how you diagnose ADHD in terms of a) b) c) and I definitely did not know that psychologists could diagnose ADHD or that there were specific tests that could be done to test for it.

*What was your reaction to the diagnosis? How did you feel? What were your concerns?*

Well, it wasn't like we were told 'your son has x' like if he were to have some major illness. It was more like he was just struggling with certain things and a trial of Ritalin was recommended. That's pretty much how we came to having Ritalin prescribed.

*What treatment options were explained to you?*

Only after I said I was not keen to go the route of medication and asked what alternatives there were, did the doctor tell me about the supplements available. He was not really in favour of them though. He went on to say that there was no evidence that they worked and that some people had good results, others didn't. I said I would like to rather explore that option. He seemed ok with that.

*What is your knowledge of available treatment options?*

I really only know of Ritalin and Concerta and Methylphenidate because we asked for something cheaper than Ritalin and then the over the counter alternative stuff – pretty much what you see on the shelves at Diskem etc.

*How were the different options explained to you?*

Well, they weren't really. It was only as time passed and as I asked more questions that I can to know more. It seems doctors offer info on a need to know basis, like they don't want to tell you too much or give you too much info all at once.

*Why do you think that is?*

I don't know. Like with Methylphenidate, I wouldn't have known about it if I hadn't asked for something cheaper. I really don't know why ...maybe they just think we will get all over whelmed if they tell just too much all at once.

*Were you given any reading material to review?*

No, it wasn't like you were given a hand out on your way out. I pretty much had to find stuff out on my own.

*What were your thought on the treatment options?*

Well, I was not going to just go out and get the Ritalin, I wanted to explore the alternative options first. I mean, wouldn't you rather have your child on something natural than on prescription meds?

I wanted to try the over the counter stuff first. I didn't just want to say ok to the prescription and go the route of meds every month indefinitely.

*Did you consider costs?*

Yes, definitely. I don't know about others but we can't just add another couple of hundred onto our monthly bill overnight. This has been really hard financially. Medical aids savings run out in about May then it's all for your own account.

*How do you feel about medication and its long term use?*

Every month I hate buying it. Every month I ask myself if it is really necessary. I don't think I will ever go and buy it willingly.

*Why do you think that is?*

I guess the cost and the fact that it's money for medication which I am not convinced is really needed.

*How did you approach making a treatment decision?*

Well, like I explained, I certainly wasn't going to just go out and get the script so during the course of the next week I went to Diskem to see what they had on their shelves. I read the boxes and inserts and spoke to the staff there and the pharmacists then decided on I think two products and started on those.

*Who did you involve in assisting with making a treatment decision?*

Well, my husband was happy for me to go ahead with exploring the alternative treatments. I spoke to friends then a lot to the pharmacy staff.

*Who was responsible for making the final decision?*

Me. I decided what to start with.

*Do you remember what products you started on?*

Some brain food thing and biostrath.

*What happened then?*

Well, for the first couple of weeks things seemed better. The teacher commented he was getting more done and a bit less all over the show.

*That must have been positive?*

It was, it really was, but it didn't last. It was so up and down. One good day, one bad day then more bad days than good days. It must have been a good six months of trying a few different natural products. Of course they all made great promises and with each one I was sure it would work.

*What social support (if any) did you experience?*

When it came to the natural products, most people said I was wasting my time so I didn't exactly feel much support there.

*Then what happened?*

The teacher called me in for another meeting. She showed me my son's work and gave me lots of examples of things he just wasn't finishing and listed books that went missing. She felt really strongly that whatever I was giving him was simply not working. She asked me please to call the doctor or to go back and see him.

*Did you?*

I did. About a week later I went in myself and he encouraged me to try the Ritalin on the basis of seeing what happened. So I went and got the script.

*And then?*

Well, of course the teacher raved about this new child in her class. I can't say I noticed much difference at home but the teacher noticed a huge difference.

*So how did you go from the Ritalin to the Concerta?*

After the first month on Ritalin I asked if there was a cheaper alternative. The doctor then prescribed Methylphenidate which was of course much cheaper. After a few months though, my son said he got bad headaches and was quite extreme in his moods. He was also starving in the late afternoon and would eat everything in sight but nothing for most of the day. We went back to the doctor and he then prescribed the Concerta and so far, so good.

*Specifically, what factors did you consider when making a treatment decision?*

Firstly, was it really necessary and the cost for sure.

*What issues were topics of discussion in considering treatment options?*

We wanted to make medication a last resort. Money is always a topic of discussion and then definitely if it was really necessary.

*Who participated in these discussions?*

Me and my husband, me and friends, me and family, me and the doctor, me and the pharmacy staff...pretty much me and whoever else would listen. It seemed to be my only topic of conversation forever.

*What additional sources of information or input were sought?*

I didn't really read much on the web. As I say, I just talked to pretty much everyone and anyone.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting medication as the treatment option?*

I remember the last time the teacher called me in, I just felt tired, like I was going around in circles. I constantly felt like I was taking one step forward and two steps back. It just seemed like I was getting nowhere fast. And as far as the teacher was concerned, things were getting worse, not better. I really just wanted to put an end to it. I didn't want to be told I needed to do something. I didn't want to feel like it was always bad news coming from the school. I was tired, I just wanted something to work. In a way I felt like I was giving in, like I had held out exploring every other option only to say 'ok, fine...I give up...I'll do what you want'.

*What were your experiences following on from this treatment?*

Well, I don't get called to see the teacher anymore. I don't get told my son isn't coping. The feedback from the teacher has been very positive. Her exact expression was 'like chalk and cheese'.

*What have been your experiences with using medication?*

I have to admit they work. They do definitely have their side effects. The loss of appetite and often sleeplessness but they do work. Particularly in terms of the focus and concentration. A lot more seems to get done.

*What have been the effects and outcomes?*

Well, for my son, he is much more settled at school, more confident in that he doesn't feel so all over the show all the time. I think there is definitely a sense of organization. We feel the effect of having to find the money every month and I am always tempted just not to get the medication and to see what happens but I really don't want to feel like I am going backwards again. It's like bitter sweet though...you get the result you want but not in the way you want. I mean, I don't know if this is something he will stay on forever now.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

I don't know. My only real comment is that this whole process was very much driven by the teacher. It certainly didn't come from me. I wasn't the one who kept saying there's a problem. My visits to the GP etc were all as a result of my many visits to the school.



I am not sure how I feel about that because it still feels like I am doing all this to make someone else happy. And it's not like something you do a blood test for, have concrete evidence for and then to take meds for. It's all pretty much opinion – the doctor's opinion, the teacher's opinion of how your child should be. I find that hard to get my head around sometimes.

*Why do you say that?*

It's just always a thought in the back of my mind...would a different teacher have said the same thing?

Respondent 4:

*What is your child's current age?* She is now 10

*Is your child a boy or a girl?* A girl

*What would you say is her general state of health?* She is seldom off school. She's a healthy child

*When was your child diagnosed with ADHD?* She was never formally diagnosed but we started medication in March this year so I guess you could say then

*What subtype has your daughter been classified as having?* Well, she is not hyperactive or impulsive but was just very slow in class, no focused attention

*What was her age at that time?* She was 9 then

*Who was your child diagnosed by?* There's that word again, diagnosed. The doctor put her on meds but the teachers have been saying for years that she had attention issues so I guess they pretty much diagnosed her

*How long after seeing the doctor did you start treatment?* We started meds that weekend

*What was that initial treatment?* Concerta 36mg tablet a day

*What was prescribed and in what dose?* That's what was prescribed at the appointment with our doctor back in March

*What medication is currently being taken and in what dose?* The same, it hasn't changed. One tablet in the morning

*What is your general understanding of ADHD?*

Dad: Personally, I think there's no such thing. I mean, there was none of this when I was growing up.

Mom: To be honest, we don't know much about cause – that's really something I have not asked about or read up on.

*Why do you think that is?*

Mom: I don't know – probably because I focus more on what it is and on the treatment.

*So how do you understand ADHD?*

Mom: Well I don't know all the technical terms but it was explained to us as the messages running to and from the brain not running smoothly or efficiently.

Dad: Not that's there's any proof of that. I bet some fancy person just dreamt that up one day and everyone has just bought into it.

*What do you know about treatment options?*

Dad: that it's either Ritalin or Concerta.

Mom: Yes, you hear mostly about Ritalin and now more and more about Concerta.

*When were you first made aware of a possible problem with your child?*

Dad: the teachers at this school have been on at us for years. All they do is go on about medicating your child.

Mom: It must have been about two years ago when the first teacher noticed Holly often used to day dream. She always seemed to finish last with tasks and activities in class.

*What was your course of action?*

Mom: Up until now we never did anything. Every year every teacher made the same comments” day dreams, wastes time, is distracted, slow, work unfinished.

*So how was a diagnosis reached?*

Mom: Well, we resisted every year. Dad: Every year we came under pressure. Every year the teacher told us she needed meds and every year we said no way?

*Was this process of formal diagnosis adequately explained to you?*

Dad: It wasn’t explained at all? What is the formal way to diagnose anyway? It all comes down to the teachers comments at the end of the day – how they say the child is in class.

Mom: I tend to agree there. We resisted year after year because we didn’t see the lack of concentration etc that they saw.

*How did you feel? What were your concerns?*

Dad: Well it’s not cool to be told your child isn’t coping at school and this big fancy label doesn’t sit well with me. Doctor’s love to have a name for everything.

Mom: in a way it felt like we had been beaten, like we had given in. but maybe we just weren’t ready before this? Maybe we were kind of like in a state of denial. There was never any formal diagnosis or a sit down where someone said here’s the big reveal. Obviously we worried about how meds would affect our daughter, how we were going to afford it. We really just started with trying the meds to see what would happen.

*What treatment options were explained to you?*

Dad: Really just Ritalin and Concerta.

*How were these explained to you?*

Mom: It was kind if loosely explained to us how the meds worked but more in terms of what we could expect to see happen over the coming days and weeks.

*Were you given any reading material to review?*

Both: No.

*What were your thoughts on the treatment options?*

Dad: You really rely on what the doctor tells you. In his professional opinion, meds were the way to go, they had the best results and were therefore most effective.

*Did you consider costs?*

Dad: Definitely but of that's what it costs, then that's what it costs. Not too much you can do about it.

*How did you feel about medication and its long term use?*

Mom: I have to admit, I wasn't thrilled about going onto medications. At that stage, we weren't really thinking long term, now what works now.

*Who did you involve in assisting with making a treatment decision?*

Dad: Just us, my wife and I.

*Who was responsible for making the final decision?*

Dad: Me. If I didn't agree it to, it was never going to happen.

*What social support (if any) did you experience?*

Mom: We have several friends whose kids take either Ritalin or Concerta and they swear by it. All of my friends that I spoke to were very supportive. Dad: Now you see, men aren't like that – we don't need to talk to every Joe soap for them to out their five cents in.

*What issues were topics of discussion in considering treatment options?*

Mom: we always came back to the words: does she really need medication? I think that's also what kept us from trying it...we never really thought Holly needed medication. Cost was also a topic. Times are tough you know.

*Who participated in these discussions?*

Dad: Just us.

*What additional sources of information or input were sought?*

Mom: Really just me talking to friends.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting medication as the preferred treatment option?*

Dad: I remember the day clearly. It was in March this year. We had both been called in for yet another parent teacher discussion. The teacher rocked up with work books, examples of things not done.

Mom: Yes, I also remember it clearly. It was the same things as always. This time it was the teacher and the Deputy Head. Their approach that day was just to try the meds and to see what happened. They asked us what we would have to lose. They said if it didn't work, then to stop it immediately but why didn't we just try it. They both implored us just to try.

Dad: So off we went to the doctor, me, my wife and our daughter. The doctor asked our daughter 101 questions and we left with a script for Concerta. That was a Wednesday. We collected the script of the Friday and started in the Saturday morning. The decision that day to get it was exactly as the deputy principal said: why not just try it, what do you have to lose?

*What were your experiences following on from this treatment?*

Mom: Our daughter is so much happier. She is more confident and outgoing. Her school work is so easy for her now.

Dad: She loves school. She is so into all her lessons. Mom: it really has been an amazing turn around. She is so much more focused, she gets so much done. There isn't that distractibility, the day dreaming, the empty pages in her books.

*Have there been any other effects or outcomes?*

Mom: The only real negative is the poor appetite. We struggle to get Holly to eat at the best of time and the first three months were ridiculous.

Dad: The child just never wanted to eat.

Mom: That seems to have settled now though.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

Mom: I am not sure. Although I see how easy she finds everything now, I don't regret not doing this sooner. Looking back though, it definitely comes from the teacher. It feels like there's a lot of coercion from them. It's like they know best.

Dad: And as I said before, this ADD /ADHD hype wasn't around when we were growing up.

Mom: These meds are part of the 21<sup>st</sup> century – pills to make us feel better, function more efficiently. Now days whatever the issue, there's medication to fix it. I guess poor concentration and distraction is just one of those issues we now have a way to fix.

Respondent 5:

*What is your child's current age?* Our son will be seven this month

*Is your child a boy or a girl?* A boy

*What would you say is their general state of health?* As a child Andrew had repeated ear infections. These settled about 2 years ago. Apart from that, he is generally well

*When was your child diagnosed with ADHD?* About 5 months ago

*What subtype have they been classified as having?* Mixed, we had issues with hyperactivity, impulsivity and inattention

*What was their age at that time?* 6

*Who was your child diagnosed by?* Psychologist

*How long after diagnosis did you start treatment?* A few days

*What was that initial treatment?* Ritalin, Half a tablet of Ritalin, so 5mg every morning

*What medication is currently being taken and in what dose?* He is still taking the 5mg daily

*What is your general understanding of ADHD?*

I understand ADHD to be a neurological thing where the wiring of the brain does not work as it should. The brain then kind of gets its wires crossed and behaviour gets a bit out of control.

*Are you familiar with what causes ADHD?*

I am not actually. I mean, I have two children, one girl and one boy. We have no issues with our daughter at all. The two couldn't be more different. They were both raised the same, obviously came from the same parents so who knows why one should need Ritalin every day and the other not. I have heard there may be some genetic link but as far as I know, no one in our family has ever showed the same behaviours as my son.

*Are you familiar with how it is diagnosed?*

Well, I wasn't but there is a psychologist who comes to the school three times a week. The teacher suggested I see him and he explained how it is diagnosed.

*And what about treatment options? Are you familiar with those?*

Sort of. I know of obviously Ritalin and Concerta and I know there is some stuff you can get over the counter but that seems to be more for the inattention, not for impulsivity and hyperactivity.

*When were you first made aware of a possible problem with your child?*

He kept getting into trouble at home for doing crazy things. He was often just silly. Trying out things that he shouldn't be, touching things he shouldn't. As a parent, I was getting quite frustrated. It was hard to be

angry with him though, he kept saying he couldn't help him. He said he was just always having this urge to fiddle with something or try something, to see what would happen.

*Who / what alerted you to any issues?*

Well, as I said, he would just do silly things at home but the final straw was when my ex arrived to collect the kids on morning. He had parked his car in the drive and come in to collect the kids things. My son said he was going out to the car so long. The next thing we heard was him screaming 'dad'. We all rushed outside and the car was rolling down the drive. He had let down the hand brake. He was so upset but just kept saying 'I just couldn't help it, I just wanted to see what would happen.' We both knew it was time for some help

*What was your course of action?*

I made an appointment to see the psychologist and told him the whole story.

*Who formally diagnosed your child?*

The psychologist.

*How was this diagnosis reached?*

After my first appointment with him, he said he needed me to complete some kind of rating scale and he asked the teacher to complete the same one so he could compare them, he also arranged with the teacher to sit in on a lesson to observe.

*Was this process of diagnosis adequately explained to you?*

Yes, the psychologist explained everything very clearly.

*What was your reaction to the diagnosis?*

I was kind of expecting it.

*How did you feel?*

I felt ok but I was a bit disappointed. ADHD means medication and I was hoping to avoid that. What were your concerns? I just didn't fancy the idea of my son taking a tablet every day. And it's not like it's a tablet for a heart condition, it's for behaviour control.

*What treatment options were explained to you?*

After the psychologist went through the results of the rating scale thingy and the observation, he said he needed me to see our doctor and wrote a referral letter for me to take with us to the doctor. The doctor didn't really explain treatment options. I explained my hesitation to use Ritalin and he said I should just try it. He said we should use it for a month then ask the psychologist to repeat the rating scale and see what the outcome was and go from there.

*What is your knowledge of available treatment options?*

I really only know Ritalin and Concerta.

*How were these explained to you?*

They weren't really. We talked only about Ritalin.

*Were you given any reading material to review?*

No.

*How did you make sense of the treatment options?*

I felt quite stuck, like there was really only one treatment option – Ritalin.

*What were your thoughts about the treatment options?*

I felt quite annoyed actually. I thought how can it be that there is only this option? I felt like I didn't really have a choice.

*Did you consider costs?*

Not initially no, more because at that first appointment we were doing the one month trial period and I had no idea how much Ritalin cost anyway.

*How did you feel about medication and its long term use?*

Well, like I said, it felt like I didn't really have a choice. It was kind of like, this is it, take it or leave it.

*How did you approach making a treatment decision?*

I was happy to do the one month trial then let the psychologist repeat the assessment and go from there.

*Who did you involve in assisting with making a treatment decision?*

It was really just me, my ex and the doctor.

*Who was responsible for making the final decision?*

Pretty much me and my ex.

*What social support (if any) did you experience?*

My parents were very supportive. Those are the only other people we discussed things with.

*Specifically, what factors did you consider when making a treatment decision?*

We considered Andrew. We wanted to do what was best for him.

*What issues were topics of discussion in considering treatment options?*

Even before the psychologist had repeated all his work, we could see it was working. He was so much more focused, less distracted and not nearly as impulsive. And when the psychologist sent us the write up from the repeat observation and assessment, it was really obvious that he benefitted from the meds. We talked a lot about his behaviour before and after meds and about whether or not we thought he would be better with them or without them.

*Who participated in these discussions?*

Me, my ex, my parents and the doctor.



*What additional sources of information or input were sought?*

None.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting medication as the preferred treatment option?*

I guess the change in behaviour. That was what made us decide. It works, the meds really work. All the behaviours that were a problem are no longer. That incident with the hand brake was horrible. And what was most upsetting was that he just couldn't help himself. He felt this loss of control and he seems so much happier. He is not getting into trouble at home or in class and he doesn't have to fight with his urge to do things. At the end of the day, we decided it was what was best for him.

*What were your experiences following on from this treatment?*

It's been really positive. I can see why doctors recommend the drug. I definitely think they have their place but I am not sure all those who take them have got about it the right way. I mean, a friend of ours takes Concerta and it was prescribed to him based on a 45 minute consult with the GP.

*What have been the effects and outcomes?*

The effects have been positive and I guess the outcome is too.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

I feel like I went the right way about things. It was important to me that if my son was going to be taking medication that there was a real need for it and the process I worked through with both the psychologist and the doctor showed me there was. I would like to see more people go about things in a more thorough manner, to make sure what you give your kids is really necessary. It's tough having to rate your child's behaviour and have someone else do that too – how much of ADHD is really just that child's personality. The idea of being able to control behaviour with medication is also a bit weird for me – when you think about it in that way, it just doesn't seem right.

Respondent 6:

*What is your child's current age?* She is now 11

*Is your child a boy or a girl?* A girl

*What would you say her general health is like?* I would say normal - she gets the odd cold but she is mostly healthy

*When was your child diagnosed with ADHD?* About two and a bit years ago

*What subtype have they been classified as having?* Mostly inattention but she can be very impulsive

*What was her age at that time?* I think she was 8 turning 9

*Who was your child diagnosed by?* Our GP

*How long after diagnosis did you start treatment?* That same week

*What was that initial treatment?* She went straight on to meds

*What was prescribed and in what dose?* Ritalin was prescribed but I don't recall the dose

*What medication is currently being taken and in what dose?* My daughter takes 36mg Concerta every morning but not during school holidays

*What is your general understanding of ADHD?*

I believe it is an inefficiency in brain functioning which makes focus and concentration more difficult – you are very effected by your surrounding environment and are easily distracted or over excited meaning both behaviour and focused attention are a problem.

*Are you familiar with what causes ADHD?*

There doesn't seem to be a clear cut cause. In most of the reading I have done, it seems to be a combination of diet, genetics, environment, individual personality traits.

*What do you know about how it is diagnosed?*

I understand diagnosis relies on parents, teachers and others like your GP rating a child's behaviour and trying to determine how much of a problem it is.

*What about treatment options? Are you familiar with different treatment options?*

These days you hear mostly about medications like Ritalin and Concerta. I know some people have had success in changing their child's diet – cutting out junk food and preservatives. Some people have found some natural products work well like that Eye Q. That's all I really know about treatment.

*When were you first made aware of a possible problem with your child?*

I can't say it was any one thing. She was always slow at doing everything, even at age 5. She used to get so busy with her toys and things that she took forever to get dressed or put on shoes. We were always saying 'come on' or 'hurry up'.

*Who / what alerted you to any issues?*

Well, her first year at school, Grade one, was really hard for her. We thought she was just taking a while to settle into formal schooling but she always seemed to be a few steps behind the others, not quite finishing things, not quite following what was going on, never really having the correct things on the correct day. Grade two just got worse as more was expected of her. At the end of the first term, the teacher met with me and my wife and told us of her concerns and really that Sam just wasn't coping.

*What was your course of action?*

At the start of the new term, we helped her get more organized. We wrote To Do lists and check lists for her to follow before leaving for school. She got a bit more organized but things didn't really change with her work in class. Midway through that term, we went to see our GP.

*Who formally diagnosed your child?*

Our GP.

*How was this diagnosis reached?*

It was after a long consult and I guess in piecing together what we were saying was a problem, what she was struggling with and the teacher had fed back to us in parent / teacher meetings.

*Was the process of diagnosis adequately explained to you?*

Well, it was never actually spelt out like 'this is how you diagnose ADHD'. Like I said earlier, it was more this process of considering what everyone says about certain behaviours.

*What was your reaction to the diagnosis?*

It wasn't as if the doctor said 'your child has x'. He said something like 'it sounds as though Sam is having some issues with...I forget exactly what he said...which may suggest...something like...a degree of inattention.

*How did you feel?*

He didn't say anything that wasn't true. He told us exactly what we knew then suggested Ritalin.

*What were your concerns?*

At that point, my main concern was that she would struggle the whole way through school and I really didn't want that.

*What treatment options were explained to you?*

No other options were explained. I asked if Ritalin was really necessary. The doctor replied that some alternative products have had some success but that ultimately people eventually come back to Ritalin after trying various other things.

*What is your knowledge of available treatment options?*

At the time I didn't know much at all. Now I know of Concerta also. I mentioned to the doctor that I had heard of Ritalin not agreeing with some children and side effects like bad headaches. He said we should try the Ritalin first and if it wasn't suitable then we could try Concerta.

*Were you given any reading material to review?*

No.

*How did you assess the treatment options?*

I really just followed what our doctor had said. I trust him and his judgment. I was happy to go with what he prescribed.

*What were your thoughts of the treatment option?*

It seems a bit extreme that we now have medication to make us behave in a certain way and focus better, I remember thinking that at the time.

*Did you consider costs?*

Not really. It was just one of those things that you add to your monthly expenses for your kids.

*How did you feel about medication and its long term use?*

I wasn't thinking long term at the time. I just really want to see results. I wanted it to work.

*How did you approach making a treatment decision?*

It's difficult to answer that because it wasn't like we were presented with options and asked to choose. It was more like, that's the problem, see the doctor, he offers his professional opinion and you do what he says.

*Who did you involve in assisting with making a treatment decision?*

My wife and I talked it over and we thought we would try it and see what happened.

*Who was responsible for making the final decision?*

We both decided together.

*What social support (if any) did you experience?*

We didn't really talk much to others.

*Specifically, what factors did you consider when making a treatment decision?*

Honestly, only one...does it work or will it work. The treatment isn't the issue, it's whether or not it works that is important.

*What issues were topics of discussion in considering treatment options?*

Well, apart from how well it would work, we also talked about the long term effects which is why we give her a break on holidays, and the costs are pretty hectic, especially as medical aid doesn't recognize it as chronic meds.

*Who participated in these discussions?*

Just me and my wife.

*What additional sources of information or input were sought?*

I googled Ritalin...that was pretty scary/ I spoke to the pharmacist when collecting the first script and he explained about the medication being quickly metabolized. He was pretty helpful and very knowledgeable.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting medication as the preferred treatment option?*

I can't say there was. To fill the script was the logical next step in the process so that's what we did.

*What were your experiences following on from this treatment?*

We didn't find the Ritalin worked well. She seemed so different. It was like her personality changed. She also complained of headaches and was pretty snappy with everyone. We also noticed clearly once the Ritalin had worn off, she was suddenly starving. After two months we changed to Concerta and have remained on that ever since.

*What have been your experiences with using medication?*

Well, apart from not enjoying the Ritalin, Concerta really works. It seriously does all that you want it to.

*What have been the effects and outcomes?*

She enjoys school. She is focused, works so much more quickly. She concentrates well, doesn't just shout out answers without thinking. She is not that forgetful anymore and she is generally more confident, I guess because she knows she is also coping now.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

It makes me realize how far medicine has come then on top of that makes me wonder what will come next. To take a tablet that makes you behave better, focus, concentrate and be more productive is insane. It's like a wonder drug. I have been amazed at the difference it has made in my daughter's life. I don't have any problem giving it to her during term time – she doesn't struggle anymore and that was all I was really concerned about.

Respondent 7:

*What is your child's current age?* He is 10 now

*Is your child a boy or a girl?* A boy

*How would you describe his general health?* He has had issues with asthma for many years, other than that, his health is good.

*When was your child diagnosed with ADHD?* About a year ago

*What subtype was he classified as having?* Mixed ADHD

*What was his age at that time?* 9

*Who was your child diagnosed by?* Our GP

*How long after diagnosis did you start treatment?* About 6 weeks or so

*What was that initial treatment?* We tried alternative supplements to start with

*When did you start medication?* About 2 months after trying the natural goods

*What was prescribed and in what dose?* Ritalin, one 10mg tablet in the morning

*What medication is currently being taken and in what dose?* Ritalin, one 10mg tablet in the morning

[Above questions answered by Mom]

*What is your general understanding of ADHD?*

Dad: At the time our doctor explained it as an inability to process information efficiently. I remember him saying it was a behavioural disorder where children found it difficult to organize themselves, to concentrate and to control their impulses.

Mom: Yes, and that sometimes children can be more disorganized and all over the show, other times more hyperactive or a combination of both.

*What is your overall knowledge of the disorder?*

Dad: Definitely nothing technical. I believe it is becoming more and more frequent and that it is noticed more when children start proper school.

Mom: These days it is really common – every other person you speak to now has a child on Ritalin.

*Are you familiar what causes it?*

Dad: Well, considering this ADHD wasn't around when we were at school and now it's common, I believe it is caused by the change in lifestyle. There is so much pressure on kids now, to cover more work, of a higher standard at a younger age. Expectations have changed and when kids can't cope, they call it ADHD and medicate.

Mom: I think it is also related to the food we eat – so much is processed these days with preservatives and colourants, surely that must play a role too?

*Are you familiar with how it is diagnosed?*

Dad: Yeah, it's based on what the teacher says about how your child behaves in class.

Mom: We both feel how it is diagnosed is a real grey area. It's not like there is a blood test or anything specific that confirm yes, you have ADHD.

*Are you aware of different treatment options?*

Dad: Ritalin, Ritalin and oh, Ritalin.

Mom: well, I know the doctors like to treat with medication but I have read about making dietary changes and using supplements and also changing the learning environment to suit the child's needs more.

*When were you first made aware of a possible problem with your child?*

Mom: I would say when he was in Grade 2. He changed schools in that year and took a while to settle.

*Who / what alerted you to any issues?*

Dad: The teacher basically. She said he was getting very little work done and that he was very restless most of the day in class.

*What was your course of action?*

Mom: We thought it was just more time to settle that was needed so we just let things be until the start of Grade 3. Grade 3 was much more challenging and he really struggled to get organized, to finish his work, so his teacher asked us please to have him assessed.

*Who formally diagnosed Don?*

Dad: We took him to an Educational Psychologist who said he was ADHD.

How was this diagnosis reached? Matt: Well, he did all sorts of assessments and asked for permission to speak to the teacher. He didn't fully explain everything.

*Was this process of diagnosis adequately explained to you?*

Dad: Not at all.

Mom: We basically met with him twice, one before he saw our son and then once more after. He just talked though results.

*What was your reaction to the diagnosis?*

Dad: I said thanks for your time and off we went. He recommended we see a GP but we didn't want that. If he had certain learning needs, we would address those, not stick him on medication.

*How did you feel?*

Mom: It's hard to hear your child needs assistance and that they are not performing as they should be. You want them to do well, to be good at everything. I was really disappointed and sad.

*What were some of your main concerns?*

Dad: That they were going to put him on meds. Mom: For me it was that he would lose his confidence and get down on himself. I didn't want that to happen.

*What treatment options were explained to you?*

Dad: Basically that ADHD was most effectively treated with Ritalin.

*What is your knowledge of available treatment options?*

Mom: Definitely changing diet and cutting out junk, there are also a selection of natural products available over the counter and to change school / study environment.

*How were these explained to you?*

Dad: When we said we were not keen on the medication, the doctor told us more about the natural products but was quick to say there is nothing substantial to say they are effective. He did mention diet being important and that's really all.

*Were you given any reading material to review?*

Both: No.

*How did you weigh up the treatment options?*

Dad: I was not keen on jumping into medication. I wanted to explore other options first.

Mom: Yes, we didn't want to have to go the Ritalin route.

*What were your thoughts and attitudes towards the treatment options?*

Dad: We didn't want to be prescribed to. We want to work out what was best for Don.

Mom: It was a bit frustrating though because our first option was not to medicate but it seemed like the doctor's was.

*Did you consider costs?*

Dad: No, not at that point, it was more about to medicate or not to medicate, not which costs more or less.

*How did you feel about medication and its long term use?*

Mom: We were not thinking long term at that stage, we just were not keen to use medication for something that we felt was based on opinion anyway and that could quite possibly be treated without new-age meds.

*How did you approach making a treatment decision?*

Dad: We insisted trying everything other than medication first. Mom: We didn't want medication to be anything other than a very last option.

*Who did you involve in assisting with making a treatment decision?*

Mom: We really just spoke about it between ourselves.



*Who was responsible for making the final decision?*

Dad: We both agreed together.

*What social support (if any) did you experience?*

Dad: You know, it's such a touchy subject – everyone has their own opinion and for their own reasons, we really didn't want to get involved in discussions so we pretty much kept it between us.

Mom: Even now, in talking to people, some are totally for medication, some not at all,

*Specifically, what factors did you consider when making a treatment decision?*

Dad: I can honestly say we considered what we thought was best for our son.

*What issues were topics of discussion in considering treatment options?*

Mom: Well, we tried two natural products in the maximum dose for around 6 weeks. We also cut out all junk food and stopped eating store bought cakes and biscuits, cokes, chips etc. Initially things changed for the positive but it wasn't consistent. Feedback from the teacher was still that he was struggling and that his behaviour was difficult, worse.

*Who participated in these discussions?*

Dad: The two of us and the teacher.

*What additional sources of information or input were sought?*

Mom: The teacher asked us to chat to one or two other parents who had put their child on Ritalin but we weren't keen. Dad: Yeah, we wanted to make our own decision.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting medication as the preferred treatment option?*

Mom: About a million times, between the doctor and the teacher, we were told 'just try it'. Looking at the work and knowing that he was not on a par with the other class members kind of made us take that step and give in so to speak. Dad: The thought of him struggling and not trying every option didn't seem right. But as said, it was like we were giving in.

*What were your experiences following on from this next treatment?*

Dad: Don't like it, never have, never will.

*What have been your experiences with using medication?*

Mom: Very mixed. It has been a difficult year. I can't deny the Ritalin works but on the meds, it just isn't him.

*What have been the effects and outcomes?*

Dad: His personality is way different, he is withdrawn, like a zombie. Sure he gets more done and is like an angel in class but that's not him. Mom: I have to agree, Don is just so withdrawn, very quiet, like he has no life in him. He has been on the medication for several months now and we won't keep him on it

once this year is finished. Our son learns in a different way. We don't think he has ADHD. He just needs a smaller class and a slower pace. The assessments done by the Educational Psychologist showed us his strengths and weaknesses and we applied to a remedial school where he will get focused attention in those areas. He will start there in January. When this year is complete, we will stop the Ritalin and go back to the natural products and focus more on changing the environment. Dad: Despite all its benefits I still feel the change to personality is not worth it. Sorry, I just can't give something to my son every day that changes who he really is.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

Dad: I just feel like more people need to really work out what's best for them and their family and not just go with the flow because everyone else is doing something. Each to their own but there are others ways to address learning difficulties. It's a very new-age approach to take medication for everything but at what cost?

Mom: Who knows what the future holds but right now this is what we feel works for us, I know we have made the right decision.

Respondent 8:

*What is your child's current age?* 8

*Is your child a boy or a girl?* A girl

*What would you say is their general health status?* Average

*When was your child diagnosed with ADHD?* Last year, early last year, I can't even remember the exact month but it was in the first term of Grade 1

*What subtype was she classified as having?* Mixed, a combination of hyperactivity, impulsivity and inattention

*What was their age at that time?* 7

*Who was your child diagnosed by?* Her pediatrician

*How long after diagnosis did you start treatment?* Shortly after, within a week definitely, maybe even a few days

*What was that initial treatment?* Concerta, 18mg daily was prescribed

*What medication is currently being taken and in what dose?* It's still Concerta but now 36mg daily

*What is your general understanding of ADHD?*

I understand it as behavioural issues in a child, where they show inattention and hyperactivity and poor concentration.

*What would you say is your overall knowledge of ADHD?*

Pretty much that, to be honest.

*Are you familiar with what causes it?*

I must admit, no, I really don't know much about that at all. The pediatrician was very vague on this. He mentioned that it can be hereditary or a child can just be born that way. I understand there are no real answers to what causes ADHD.

*What about how it is diagnosed? What do you know about that?*

Well, that there is a kind of check list that you go through with the doctor, something like 'does your child have or do x, y, x'. Also observation – the doctor spent about 45 minutes to an hour observing her throughout the appointment.

*What do you know about treatment options?*

Obviously what a child eats is important although I am skeptical regarding that – it's not effective and ADHD is not that simple. It's more common sense that if you eat well, it's better for you. I obviously know Ritalin but our doctor was pro Concerta as a slow release tablet so he kind of promoted that more than anything.

*When were you first made aware of a possible problem with your child?*

When she was in Grade R.

*Who / what alerted you to any issues?*

The teacher at the time and then my husband and I had our own concerns.

*What was your course of action?*

Well, after speaking with the teacher, we saw an educational psychologist who did some assessments.

Nothing really happened after that as we thought maybe she was just settling into the new environment.

*Who formally diagnosed your child?*

The pediatrician at the beginning of Grade 1.

*How was this diagnosis reached?*

Well, we still weren't really happy with behaviour, home life was a nightmare but at school the teachers didn't really see the same so I finally made an appointment to see the pediatrician.

*Was the process of diagnosis adequately explained to you?*

Um, yes, I guess.

*What was your reaction to the diagnosis?*

Very mixed feelings. It's never nice or easy for a parent to hear there is something wrong with their child but it gave us a better understanding of what was going on with her and being medicated really does work.

*How did you feel?*

Mixed, sad but hopeful.

*What were your concerns?*

Initially, medicating our child. The idea of her being so young and being on medication which would possibly be for a long time.

*What treatment options were explained to you?*

Really not much, pretty much Ritalin and Concerta. The doctor believed Concerta was the way to go, he was not convinced about trying different diets and other supplements. He pointed us in the direction of Concerta and we trusted him.

*Was this treatment option adequately explained to you?*

I guess, he talked quite a lot about how the meds will work.

*Were you given any reading material to review?*

No.

*What were your thoughts on the treatment options?*

We didn't know enough about Concerta, our thoughts were more on her being on meds indefinitely but we were so desperate we would have tried anything at that stage.

*Did you consider costs?*

Yes and no, the Concerta was more expensive but we were happy to pay more for the recommendation...thank goodness for medical aid.

*How did you feel about medication and its long term use?*

We were nervous about it but saw it as a necessity. Things could not continue the way there were. Our whole family life was disrupted.

*How did you approach making a treatment decision?*

To be honest, we talked at length to the doctor then went to collect the script. We relied on the doctor's opinion and his recommendations.

*Who did you involve in assisting with making a treatment decision?*

No one other than my husband and I. Who was responsible for making the final decision? Both of us. What social support (if any) did you experience? None, we told family members afterwards, once she had been on the meds for a few weeks.

*Specifically, what factors did you consider when making a treatment decision?*

Our reservations of long term meds vs the need to do something for her. As I said though, we both knew the situation couldn't continue as it was.

*What issues were topics of discussion in considering treatment options?*

Nothing really, we discussed on concerns about the actual medication and how it worked in the appointment with the specialist.

*Who participated in these discussions?*

The two of us and the specialist. But Sally had become so disruptive in the family unit and our focus was more on a solution.

*What additional sources of information or input were sought?*

I googled ADHD and Concerta but that was about it. I did also chat to our GP.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting medication as the preferred treatment option?*

No, not at all, it was a build up over a long time, over nearly a year that contributed to it. The behaviour was just too much with no improvement, in fact, it was getting worse, and for the sake of our own sanity and for our younger child, we knew we needed professional help. We lived in the hope of things settling down, but they never did.

*What were your experiences following on from this treatment?*

Initially it didn't make much difference; so we went back to the paed and the dose was increased from 18 to 36mg after two months. Then we saw a significant difference. Prior to medication, my daughter could

not sit and watch a movie from start to finish. Now she will sit and watch, now she will sit down and listen to a story. We see the first half hour in the morning, she is manic, no concentration, hard work, and then the meds kick in and she settles and is so much more manageable.

*What have been your experiences with using medication? What have been the effects and outcomes?*

I would say positive. She is however not a good sleeper but is that ADHD or the medication? Definitely there was a loss of appetite which seems to have sorted itself out. She lost weight at the beginning but now her weight and appetite are fine. The positives have far outweighed any minor negatives.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

My only thing based on my personal experiences is that, I would highly recommend for parents to keep their children constantly on their medication. I cannot understand your child not being medicated on weekends or on holidays. The meds are not something to make the teacher happy. It has a huge effect on the family and it's not something that just goes away. The reality of ADHD is that you can have a real problem. Family life becomes unbearable and my daughter recognized the change in herself and in her relationships with others. It seems such a big thing to put a child on medication. Everyone talks about drugging a child to make life easier. There is a lot of judgment. There are many preconceived ideas and stigma but the reality is, it needs to be controlled, for your own sanity and for the benefit of whole family. I have definitely seen the benefits. My only other comment is that there was no real follow up from the doctor, you pretty much get your script every month and carry on and if you have any issues, it's up to you to go back and see the doctor. Feedback is more from the teacher, I guess they experience the child all day and are in a better position to say whether or not you are on the right track.

Respondent 9:

*What is your child's current age?* 9

*Is your child a boy or a girl?* A boy

*What would you say is their general health status?* Fair, he does pick up the odd bug

*When was your child diagnosed with ADHD?* It was in about the second term of Grade two, about 18 months ago

*What subtype was he classified as having?* He was impulsive with inattention

*What was their age at that time?* 7

*Who was your child diagnosed by?* Our family GP

*How long after diagnosis did you start treatment?* The very next day

*What was that initial treatment?* Concerta 18mg daily

*What medication is currently being taken and in what dose?* The dose was just increased a month ago to 36mg

*What is your general understanding of ADHD?*

It's when children have difficulty controlling their impulses and battle to concentrate or stay focused.

*What would you say is your overall knowledge of ADHD?* It's difficult to define the term, but I can describe what it's like so I suppose my knowledge is more practical.

*Are you familiar with what causes it?*

No, but then again, I don't think many people are, even doctors. There doesn't seem to be a single, definitive cause.

*What do you know about how it is diagnosed?*

I know that it comes down to how a child behaves, that there are certain behaviours that are typical in ADHD children and that if you watch them in a class environment for example, these will be seen/

*What do you know about treatment options?*

I know some people promote eating in a certain way and there are some health supplements that claim to work wonders but I think the most effective treatment is medication like either Ritalin and Concerta.

*When were you first made aware of a possible problem with your child?*

Towards the end of Grade 1.

*Who / what alerted you to any issues?*

First it was the teacher then we also noticed at kids parties that he was always a bit more silly than the other boys.

*What was your course of action?*

The teacher said she was concerned mainly about his focus and concentration and that he was easily distracted. She suggested that we monitor him then talk again towards the end of the term. In Grade 2 the new teacher said almost exactly the same but that it was worse as the work was more challenging and he was starting to fall behind.

*Who formally diagnosed your child?* Our GP.

How was this diagnosis reached? The teacher suggested we see our GP for a full medical to make sure there was nothing else going on. She also wrote a letter with her concerns and describing his behaviour in class. We saw our usual doctor and he read the letter, asked us a million and one questions and also asked Jo a few things.

*Was the process of diagnosis adequately explained to you?*

Well, it was described as an assessment of behaviours and the extent to which they are a problem.

*What was your reaction to the diagnosis?*

We expected it, you don't go to the doctor complaining of poor attention, lack of focus and being distracted and not walk away with a script for either Ritalin or Concerta. I felt my heart sink though. I didn't want to believe it was our son, that he was like joining the ranks so to speak. But it wasn't a total shock.

*How did you feel?*

I was ok actually. It was like, ok, so let's try this and see what happens. It was a real positive for me that he could be given him something that had the potential to really work. .

*What were your concerns?*

I was concerned about side effects – we had heard of insomnia and weight loss so we worried about that mainly.

*What treatment options were explained to you?*

That there were two options: Ritalin and Concerta but that Concerta was better as it was a slow release drug so worked more effectively for longer.

*Was this treatment option adequately explained to you?*

It was explained to us how it worked and some of the common side effects to expect, that's really about it. Oh, and to give it as early in the morning as possible.

*Were you given any reading material to review?*

No.



*What were your thoughts on the treatment options?*

Well, we went to the doctor for a reason and if that was his professional opinion, then we were happy to go with it. The issues weren't getting any better, in fact, they were getting worse so we needed to help our son in one way or another and if this was shown to be the more successful route, then so be it.

*Did you consider costs?*

Sort of, we knew it was going to be an extra expense, but what choice do you have?

*How did you feel about medication and its long term use?*

We weren't really thinking long term at that stage. We of course asked a couple of times if the meds were really necessary and the doctor assured us nothing would work as well as what he was recommending.

*How did you approach making a treatment decision?*

Like I said, we went with what the doctor suggested – we came with the problem, he told us of the best way to address it. We were happy to go with his expert knowledge.

*Who did you involve in assisting with making a treatment decision?*

We talked between ourselves both in the doctor's room and after the consult. We spoke a lot to the doctor about side effects, dose and stuff like that and then when we went to get the script, we talked more to the pharmacist.

*Who was responsible for making the final decision?*

We were both happy to move forward in the way that was recommended.

*What social support (if any) did you experience?*

We had a lot of positive feedback and encouragement from other parents whose kids were already on Concerta – they were all happy to give advice, tell their stories so that was really nice.

*Specifically, what factors did you consider when making a treatment decision?*

We weighed up leaving things as they were or starting the meds and then, if we were going to start medication, would its benefits outweigh the expected side effects.

*What issues were topics of discussion in considering treatment options?*

The burning question was is it necessary followed by is it going to work.

*Who participated in these discussions?*

Us and the doctor and us and the pharmacist.

*What additional sources of information or input were sought?*

I would say really just talking to other people and listening to their experiences.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting medication as the preferred treatment option?*

Not a defining moment, no. it was just the feedback that things were getting worse and that our son was falling seriously behind. We both agreed we needed to do something as there was a one way pattern emerging. We couldn't ignore that there was a problem and how long can you sit back and watch your child struggle and not do anything about it.

*What were your experiences following on from this treatment?*

The teacher noticed a change the very first day. His concentration was so much better, he was more productive, he finished things so much more quickly. It really just gave him the boost he needed, it kind of fine-tuned his senses. At home he was also more involved, more lively. We noticed him being much happier – he seemed to be much more in control.

*What have been your experiences with using medication?*

Really, all very positive.

*What have been the effects and outcomes?*

Look, there's no denying it works, the stuff really works. He has really blossomed at school and his confidence has really improved too. There was a serious decrease in appetite but more so in the last few months when we increased the dose to 36mg. The initial dose worked well but after a real growth spurt, it wasn't as effective. We expected more hectic side effects but apart from eating less, there hasn't really been anything.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

When it comes to medication, I wouldn't say yes, medicate at the first sign of a problem but if you aren't getting the results you want, and if things are getting worse, then you should be open to listening to what other people say. Doctors and specialists deal with this every day and you have to trust their judgment and have faith in them that they will do what's best. But when it comes to your kids, it's difficult to separate all the issues and to know what's best for them. At the end of the day, you really just want to try and work out what the right thing is to do and then to do it.

Respondent 10:

*What is your child's current age?* 9

*Is your child a boy or a girl?* A girl

*How would you describe your daughter's health?* Typical, well the majority of time but definitely gets the odd cold

*When was your child diagnosed with ADHD?* Now 9 months ago

*What subtype was he classified as having?* Mixed

*What was their age at that time?* 8

*Who was your child diagnosed by?* Our family GP

*How long after diagnosis did you start treatment?* The very next day

*What was that initial treatment?* Concerta 18mg daily

*What medication is currently being taken and in what dose?* The dose was increased after two months to 27mg Concerta

*What is your general understanding of ADHD?*

Shew, I haven't really ever thought about defining it but it is a behavioural condition which effects mainly school work and concentration and focus.

*Are you familiar with what causes it?*

My GP wasn't able to really answer that question. I think it's a bit of a grey area. I think it can be inherited.

*What do you know about how it is diagnosed?*

Well, it's an assessment of behaviour and how much that behaviour gets in the way of school work and other activities.

*What do you know about treatment options?*

That it is most effectively treated with medication like Ritalin or Concerta.

*When were you first made aware of a possible problem with your child?*

At the beginning of Grade 2, last year.

*Who / what alerted you to any issues?*

The teacher. She said Jane wasn't coping with her attention and that she was slow to finish things.

*What was your course of action?*

The teacher asked us to monitor things at home and then for us to meet again in a month. She still had the same concerns after the month so she asked us to talk to our GP.

*Who formally diagnosed your child?*

Our GP.

*How was this diagnosis reached?*

We went to the doctor as the teacher recommended. He spent ages with us asking all sorts of questions. It was a long appointment, maybe 45 minutes. Then he suggested Concerta.

*Was the process of diagnosis adequately explained to you?*

No, not really. The appointment was more like an investigation into what was going on.

*What was your reaction to the diagnosis?*

The doctor said something like 'Jane appears to be showing symptoms of inattention...' and that he would like to put her on a trial of Concerta. We said ok and went along with what he was telling us. It didn't seem that much of a big deal.

*How did you feel?*

Obviously I would prefer my child not to have to take medication everyday but if this is what is going to help her, then so be it.

*What were your concerns?*

I asked about side effects and about costs. Those were my real concerns.

*What treatment options were explained to you?*

The doctor talked about Ritalin and Concerta but he said he preferred Concerta so wanted to go with that.

*Was this treatment option adequately explained to you?*

Not really in terms of how it technically worked but more in terms how it should be taken, the results you can expect on it and common side effects like loss of appetite and insomnia.

*Were you given any reading material to review?*

No.

*What were your thoughts on the treatment options?*

I was actually keen to get started to see what was going to happen, if there would be an improvement.

*Did you consider costs?*

I did. But it's kind of just one of those things you have to factor into your monthly expenses.

*How did you feel about medication and its long term use?*

We don't really think long term. We go day by day, month by month. I suppose no medication is always better for you health wise but if you need it, you need it.

*How did you approach making a treatment decision?*

We were fine to do what the doctor suggested. If that was his professional judgment then that's what we do. In the long consult we talked about the medication at length and we were due to see him again for a follow up. I was happy with that.

*Who did you involve in assisting with making a treatment decision?*

My husband and I talked about it. We didn't involve anyone else in that. Oh, and I did talk to the pharmacist when I collected this script.

*Who was responsible for making the final decision?*

Both of us, we both thought it was worth a try.

*What social support (if any) did you experience?*

Well, quite a few kids at the school are on either Ritalin or Concerta and the parents all say how their child couldn't go without their meds. It was encouraging to know they obviously work.

*Specifically, what factors did you consider when making a treatment decision?*

I would say it all depended on the results. We were happy to proceed with meds if they worked, if there really was a difference.

*What issues were topics of discussion in considering treatment options?*

It was a combination of does she really need it and how well do you think it will work.

*Who participated in these discussions?*

Me and my husband, the doctor and then the pharmacist when I collected the meds.

*What additional sources of information or input were sought?*

Just talking to other people and the pharmacist.

*Was there a specific pressure or issue, an occurrence or defining moment which ultimately lead to selecting medication as the preferred treatment option?*

I think we very much went with the doctor's opinion. This is what his feedback was and this was what to do about it so we went with it.

*What were your experiences following on from this treatment?*

I think we went back to the doctor after two months. There had been some improvements but not as drastic as we had expected. The doctor then upped the dose to 27mg daily and then we noticed a huge difference.

*What were your experiences using the medication?*

Well, once on the stronger dose Jane was focused, her concentration was excellent. She worked more quickly, she no longer finished last in class or started something that never got finished. She just coped so much better with all aspects of her day at school. The feedback from the teachers was also all positive.

*Any negative side effects?*

Just really the loss of appetite but then Jane was a little chubby at the time so that actually also worked out well. Her appetite has returned to normal now though.

*In retrospect, do you have any specific insights, regrets, suggestions and / or recommendations?*

I know there are a lot of different opinions on medications for ADHD but for us, if you have the chance to help your child get ahead then you should make use of that opportunity. We have never looked back. I wouldn't have it any other way. So she's on medication, so what – she is doing so well at school, her confidence has grown, she is generally so much happier...what's so bad about that?

End